

**Strategic lay forum**

 Wednesday 22<sup>nd</sup> February 2023, 09:30 - 12:00

In-person and via Microsoft Teams (online)

<b>Strategic lay forum attendance:</b>	
Trish Longdon	Chair
Ed Lowther	Co-chair
Shanaka Dias	Co-chair
Graeme Crawford	
Jane Wilmot	
John Black	
John Norton	
Sonia Richardson	
Phayza Fudlalla	
<b>Other organisations and Trust attendance:</b>	
Anne Middleton	Deputy chief nursing officer
Bob Klaber	Director of strategy, research and innovation
Sanjay Gautama	Consultant anaesthetist
Kevin Jarrold	Chief information officer
Clare Leon-Villapalos	Intensive care nurse and clinical practice educator
Andy Worthington	Deputy chief nurse
Raymond Anakwe	Medical director
Hannah Franklin	Strategy, research and innovation programme manager
Ian Lush	Director of Imperial Health Charity
Janice Sigsworth	Director of nursing
Linda Burridge	Head of patient and public partnerships
Maria Piggin	PERC (Patient Experience Research Centre) partnerships and training manager
Michelle Dixon	Director of engagement and experience
Michelle Knapper	Clinical review and elective patient experience lead
Meera Chhaya	Community engagement manager
<b>Apologies:</b>	
Darius Oliver	Associate director of communications
Clare Hook	Chief operating officer
Joanna Fisher	Deputy director of nursing, surgery, cancer & cardiac sciences
Rachel Watson	Head of user insights and experience

1.	<b>Welcome and apologies – Trish Longdon, chair, strategic lay forum</b>	<b>Action</b>
	Trish opened the meeting and the apologies were listed.	
2.	<b>Health equity – Dr Bob Klaber, paediatrician and director of strategy, research and innovation</b>	
	<p>Trish welcomed everyone in-person and virtually and handed over to Bob to discuss health equity.</p> <p>Bob explained the meeting is a great opportunity to get everyone up to speed on the health equity work. In July and October 2022, Bob and Hannah presented papers to the executive team which outlined a plan on a page about what they are planning on doing. Bob explains conversations regarding health equity have been going on for 20 years however this has always been placed in the difficult box. Thus, one benefit of COVID was to bring these issues to light (i.e. vaccinations) and what Bob has tried to do is maintain the momentum on this issue. Bob mentioned that everyone is very passionate about giving the best possible care for everybody, not just for the people that are able to get it. The whole purpose of an integrated care system is to improve population health and equity and none of us want to deliver inequitable care.</p> <p>BL refers to the diagram and four key priority areas:</p> <ol style="list-style-type: none"> <li>1. <b>Make our outpatients services more equitable and improve productivity by significantly reducing disparity in DNAs over the next 12 months as measured by both deprivation and ethnicity</b> Trust gastroenterology and ophthalmology patients contacted to understand reasons for DNA. GP and staff insights also being gathered Helix / Change Lab project team mobilised to scale this to five specialities, community co-production and piloting interventions to increase attendance.</li> <li>2. <b>Deliver equitable elective services recovery by conducting an in-depth review to identify and tackle inequities in how long patients are waiting and their experience while doing so.</b> Analysis of wait times by ethnicity / deprivation / age / sex underway –early findings do not indicate any patient group is waiting longer (i.e. not an access issue). Qualitative insight gathering to complement this being scoped. Interventions likely to focus on experience of waiting and ‘waiting well’ support (which might have some outcomes impact) for underserved groups, including support from Imperial Health Charity support grassroots organisations provide these for trust patients.</li> <li>3. <b>Make patient experience at Imperial more equitable by reviewing feedback mechanisms, tackling language barriers (including improving access to translation services) and diversifying and increasing community engagement</b> Equity focus included in Outpatients digital and communications user insights research, and ‘end of life’ care.</li> </ol>	

Next phase of user insights work scoping experience / equity / improvement ward focussed intervention.

**4. Contribute to reducing inequities in health outcomes by implementing targeted smoking cessation interventions**

Extensive review of Trust baseline provision completed - diagnostic and recommendations put to EMB in February paper.

Also initiating local improvement projects and scoping staff smoking cessation offer.

Bob mentions what is key is to make intelligent actions that are based on the inequities people are suffering from.

Bob refers to the diagram on page five and explains this is called a fishbone diagram because it looks like a fishbone. This is an important improvement tool and requests for Hannah to explain.

Hannah explains the gastroenterology team have been really supportive in lending their time to proactively ask patients who didn't attend their appointment, why they didn't attend. This has never been systematically done in the Trust before. As a result, Hannah was able to contact four weeks' worth of gastroenterology patients who failed to attend their appointments. These patients fell into two groups; deprived communities (used postcode) and ethnic minority. Hannah mentioned they weren't able to get hold of everyone but attempted contact three times. Hannah explains the process has been an interesting bit of learning. In total, Hannah was able to get hold of 54 patients and of those, 39 felt happy to take part in the service evaluation (which fits with the QI approach). Hannah explained the data illustrated the main patient driven factors were transport, accessibility, knowledge, personal and administrative. Hannah has a meeting with the gastro team to work through this and start implementing some changes.

Trish comments by saying this is very positive and well-presented but in essence this is a professional view point which is the purpose of lay partners being here. Trish mentions that it is great Hannah is actively speaking to patients and that the improvement methodology is being used with real rigour; thus putting method in place.

Phayza adds this is brilliant to see and well done to Hannah and her team. The work will make a big difference to patients' wellbeing when asking why they did not attend their appointments. Phayza mentioned volunteers (if well trained) can help to collect the feedback from patients.

John Black agrees with the volunteer support.

Phayza asks what actions and approaches will be adopted to enable these patients to attend their next appointments.

Bob explains this isn't an intervention but a cover sheet that really forces people to go through the questions patients face.

Shanaka adds this is a great initiative and it's heartening to see this coming through. The main point he would like to bring across is about the people who chose not to respond and the people that weren't able to get in touch with after three calls. Survey information or following up with patients can often be self-selecting. Shanaka mentions why they didn't attend and the information

	<p>you don't get can also give you information. For example, there would be demographic information for the people who chose not to respond, i.e. ethnicity that you can add to your data. Plus, the people that did not attend are most likely going to attend their gastroenterology appointment at some point, which maybe a further opportunity to follow up with them. Shanaka is conscious that Hannah is working with a sample set and it would be good to broaden it to ensure all bases are covered. Apart from that, Shanaka believes it is a great initiative and looks forward to seeing where it goes.</p> <p>Bob emphasises this is an aspirational but serious piece of work which has real depth and rigour.</p> <p>Anne highlights that with regards to the patients not responding, it would be important to reach out and utilise community networks and faith groups because that's where you could potentially retrieve in depth answers, creating greater meaning and understanding. Anne mentions the second point is a wider issue around the impact within nursing, i.e. health inclusion and empowerment which sits within Anne's portfolio. Anne is very keen to come back at a later date to discuss this further with the group.</p> <p>Trish concludes by saying there have been interesting conversations with actions which will be taken forward outside the meeting. Trish thanks Bob and Hannah for their contribution and requests if anyone has any more thoughts, to put them in the chat.</p>	<p>Anna to come back at a later date to discuss health inclusion and empowerment within nursing.</p>
<p><b>3.</b></p>	<p><b>Use of digital applications to manage healthcare bookings and support communications between patients and providers – how can we ensure they are integrated and user-focused? Kevin Jarrold, Chief information officer, Information, communications and technology, Sanjay Gautama, Consultant anaesthetist, chief clinical informatics officer &amp; Caldicott guardian</b></p>	
	<p>Trish welcomes Sanjay and Kevin to the forum. Trish mentions one of the areas lay partners are keen to get involved in is digital and equally there is openness to have lay people involved. Trish explains to Sanjay and Kevin that they are interested in starting a conversation to understand who is taking hold of this from a user point of view.</p> <p>Kevin highlights there is absolutely an open-door policy and the reason for this is because he has seen how well the partnership works. The classic example is the Care Information Exchange which is now the largest patient portal in the country. The expectation for next month is to pass the half million mark of patients who have activated their accounts. Lay partners were pivotal in enabling this to move forward and it was the commitment from the charity that provided the funding to set this up. Kevin explains both he and Sanjay have remits that sit within Imperial, the acute provider collaborative, but also across the whole of North West London. Kevin explains they have also been working with Bob and Michelle to shape this.</p> <p>Sanjay is hoping colleagues will know the patient voice has always been part of the digital and data strategy. John Norton has been on this journey, not just in North West London and Imperial but across London. Sanjay explains developments have been over a decade and he and Kevin have been very clear that one of the key parts of the seven steps to heaven is patient</p>	

contribution, in the form of having access to their records. Sanjay highlights the change in wording where the focus is about patient and resident empowerment and taking control of one's health and wellbeing. Sanjay adds there is a partnership as it has to work for our residents and patients. The patient experience has to be seamless. Sanjay emphasises the need to hear the patient voice and build on that. From a clinical perspective, Sanjay reflects the aim was to get the right apps in the right place at the right time so a seamless experience can be provided to the clinician. Sanjay highlights the same approach needs to be applied for residents and patients and believes they have the best platform to get this started.

Bob highlights the change in language is very important. This is due to the conversations with lay partners who push for change. Another important point Bob highlights is about data and research as there is real opportunity to do something which has not been done before.

Shanaka gently challenges the patient empowerment term. Shanaka highlights it is about patients, thus what matters to you maybe better terminology.

Sanjay agrees there needs to be focus on getting the language right for different audiences. The patient empowerment language is what Sanjay has used clinically and operationally so they understand what they are trying to achieve. Sanjay highlights Michelle has supported with this and that they will make an effort to get the language right dependent on audiences.

Phayza is concerned about digital poverty and vulnerable people accessing services and is keen to understand what actions and support will be provided for them.

John Norton mentions at times it can be lonely as the only lay partner on this programme. John makes a plea that if there are lay partners within our group and the wider lay partnership of Imperial who have a particular interest in helping to bring the patient voice to bear, to get involved. John explains you do not need to be digitally qualified as the technical elements are managed by the experts. However, those experts need guidance in what the public and patient require.

Olivia is pleased to hear there are a lot of aspirational things happening. Following on from what fellow lay partners have said about what matters to you, Olivia highlights the importance of going back to basics, for example, at the moment, there is no user forum provided by patients. Olivia stresses the importance of starting this up as it is part of the contract, which is a central way to find out what patient's want. There is a lot going on from a strategic level but Olivia mentions it is important to take a step back and look at the practical level.

Kevin mentions the feedback is really helpful and will focus on how they can address these points, particularly around patients having to reschedule their own appointments. Kevin highlights once this is established within the acute provider collaborative, they will explore whether this can be used more widely across other parts of the NHS.

Sanjay adds that it is entirely reasonable to keep the process as simple as possible but there is a middle ground to be found. Sanjay and Kevin hope to

	<p>push a single way for patients to access their records. Sanjay highlights the comments about digital exclusion and managing that appropriately. Digitally, Sanjay reassured the committee that nothing is going in without a fall back being implemented that sits on standard processes, i.e. letters.</p> <p>In terms of thinking at a London level, Kevin explains Sanjay has a remit that is London wide which involves regular meetings with four other integrated care systems. One of the frustrations to patients is that clinicians do not necessarily see records that are generated elsewhere in London. Thus, Kevin highlights the rolling out of the London care record, which is available across Imperial and Chelsea and soon across London, Northwest Hillingdon.</p> <p>Sonia adds that it is mind-blowing that hospitals have so many systems and highlights Kevin and Sanjay have a huge job to do to make it coherent and comprehensible to people who are less familiar with some of the systems.</p> <p>With reference to Shanaka's comments on 'what is it that you want us to do?' Michelle highlights they are almost starting with the groundwork. Thus, Michelle adds what will come out of the research is the comments which have been mentioned today. It doesn't matter how complicated it is behind the scenes, it's what is feels like on the front which is important. Thus, there is more work to be done to make the process simple.</p> <p>Trish asks Sanjay and Kevin how the lay partners can support.</p> <p>Sanjay explains the next stage in the process is the research which will start to drive out some thoughts and actions. Sanjay will reflect on the comments from today's meeting and is very happy to feedback going forward.</p> <p>Trish explains the lay partners are happy to co-design and are interested in a solution as Sanjay and Kevin are more familiar with the strategic issues.</p> <p>Kevin and Sanjay agree with this statement.</p> <p>Trish thanks Kevin and Sanjay for their time.</p>	<p>Michelle to think about how the lay partners can understand this piece of work.</p>
<p><b>4.</b></p>	<p><b>Minutes, action log and brief updates on projects - Linda Burridge, head of patient and public partnerships</b></p>	
	<p>Linda explains the next section will focus on the minutes, action log and brief update on projects. In terms of the minutes, Linda asks whether anyone has any comments.</p> <p>Trish explains she has one point. There is a comment in the minutes where she paraphrased Tim's commented regarding the ICB and ask for this to be removed.</p> <p>Linda leads the conversation to the actions points where focus will be placed on the ones where questions were raised.</p> <p>The first action point is on remuneration. Following on from a meeting with Clemmie and Meera, Linda explains the process that is currently in place is very complicated. If we want this to happen in an easy to manage way we</p>	<p>Amend Tim's comment on the ICB on page 4.</p>



	<p>how we cross-over the work around equality. Linda circulated the recent anti-discrimination and anti-racism statement and asks whether there is an update.</p> <p>Michelle highlights the lay partner intervention has driven a lot of change in the anti-discrimination and anti-racism engagement. Michelle states the project is going back a step where it is being viewed as a continuation of the work in 2017 which focused on the co-design of the values and behaviours. Thus, building on this as part of a culture change. Michelle highlights the need to include everyone; patient, community and staff. Thus, lay partner input has moved this along quite quickly.</p> <p>In terms of user focus, Michelle will be providing an update on this.</p> <p>In terms of community engagement, Linda highlights there is a national programme which is happening in the maternity services called 'maternity voices'. Linda met with the midwives to discuss this further, as with the CQC visiting that area, they are keen to ensure it is as effective as possible. Positively, Linda explains the midwives are keen to attend community engagement meetings, thus they will be going to the next BME Health Forum. Linda explains this is one step but is aware of the wider area of work that needs to happen around this.</p> <p>Phayza mentions there are maternity champions trained by Public Health and wonders whether it would be a good idea to link with them.</p> <p>In terms of the strategic lay forum business planning meeting, Linda states there is a session on this later in the meeting which will be really helpful in identifying what our focus will be.</p> <p>Trish thanks Linda for the update.</p> <p><b>BREAK</b></p>	<p>Meera to set up a meeting with those involved in the NW London collaboration projects (the acute care collaborative, community diagnostic hub and the elective orthopaedic centre consultation).</p>
<p><b>5.</b></p>	<p><b>Developing user-focused and personalised care through the 'what matters to you initiative' - Trish Longdon, chair, strategic lay forum</b></p>	
	<p>Trish welcomes everyone back. Following on from the business planning away day, Trish mentioned there were concerns that the patient centeredness had lost some of its energy and momentum especially during the pandemic. Given how hard things are for people, the question raised was how we can re-establish the importance of this which isn't resource intensive and consequently makes the patient and working life better. Trish explains one of the things lay partners pushed for last year was what matters to you. Trish hoped the Trust might do a pilot of what matters to you which is evaluated properly and then rolled out in a way which feels positive. Trish explains this did not happen last year but Janice and Anne mentioned they were interested in this and linking it to pathway to excellence. Trish explains the aim is to take this forward in a positive and constructive way.</p> <p>Janice explains she has been interested in this for a long and it's good to have the lay partners championing this. Janice explains the next step is to put together a proposal which can be taken to the executive committee to get executive support before a pilot is started. Furthermore, Janice states wards and departments need to be identified as it should not be the responsibility of</p>	



her team to make these decisions. Additionally, Janice explains depending on the department, the same methodology may not be applied, i.e. we might do a lighter touch or detailed approach. Janice explains it's important to draw on the literature and research to support this. Also, what outcomes are we looking for and how are we going to measure this to show a difference. Janice suggests the best way to do this is in a multidisciplinary team, i.e. the board round work.

Anne explains she is integrating a similar approach with people with learning disabilities and stresses the importance of having similar approaches to ensure the work is evaluated properly.

Trish asks Raymond for his input and explains the lay partner forum would like to put some initial work on what matters to you into the business priorities for this year. Trish asks whether there is a way of taking this forward with lay partner support.

Raymond highlights being user focused is very important but he has not had any conversations around what matters to you and had not heard of it until this meeting. In terms of how we take this forward, Raymond stresses the medical directors office will not be able to support as they have their own set quality priorities.

Michelle highlights what matters to you is a simple concept but it does mean different things to different people. There was a pilot which was led by the QI team but focused on gathering feedback. Michelle mentions this isn't the pilot Trish is talking about. Michelle highlights the priority at the moment is gathering all the feedback from the user insight and function workshops. The next workshop is on Friday 31<sup>st</sup> March and will focus on this feedback. Tim is very supportive of this. The group also discuss Dr Anne Kindlerler, a consultant rheumatologist's, use of 'what matters to you'. Linda recorded a video interview with her where she discusses this as part of her care.

Trish discusses Anne's video where there is a patient who is in a lot of pain and comes into clinic. The young woman explained she is starting a course in design and mobility is really important and pain is less important as she wants to be able to move her arms fully. Thus, Anne dealt with this based on that conversation. Trish explains what's important is saying to the patient at the start of their care 'what matters to you' and working with the patient to deliver this.

Raymond made the point that what we are describing is good clinical care which is standard and normal human behaviour. What Michelle was describing was a QI project which Raymond sees as helpful. If you are adding an ask for clinicians, you need to be very clear what you are asking or what they are currently not doing. Raymond mentions that if a pilot has not been completed, then doing a trust wide programme seems like quite a leap.

Trish explains the aim is to complete a pilot. The suggestion is we have never had a multidisciplinary team approach to this and is that possible; could this be done in a small area with QI support and appropriate evaluation. Trish explains the idea is to do something quite contained.

Raymond agrees that being user focused is the right thing to do but the question is what we are asking.

Michelle agrees and says we need to go back to go forward but there is a lot of literature from IHI supporting this. Michelle states this sits with the culture work.

Trish highlights this isn't everybody's clinician practise. It maybe the doctor asks the patient but then if the doctor has not told anyone else, the physio may end up doing something different. Without sounding patronising, Trish explains there isn't good practise at the moment.

John feels this is no more or less on what is already fully established, i.e. patients should be involved in their care. John suggests long term care (or end of life care) would be the main beneficiaries of this where the patient would have had quite lengthy conversations about their care. John explains this isn't anything new but a recognition of the patient being involved in a partnership. John views this as a cultural shift.

Anne thanks John for this comments. Anne explains we do not have the same response as mental health or learning disabilities in terms of monitoring how we engage with patients in their care and treatment plan. Anne agrees with Raymond that if we are having consensual discussions with our patients, we should already be doing this anyway. Thus, we need to agree as a collective what we are going to do. Anne believes it is a multidisciplinary piece of work with QI support. Thus, more conversations need to be had.

Janice agrees with Raymond. In terms of clinical staff, we have to be clear what the problem is we are trying to solve. In many ways the Trust has not got a major problem around this despite how important we think it is. In terms of long-term care or specialist conditions, patients review their care very well. The elderly who come through A&E with more general problems get the least good experience. It may add value to learning disabilities, autism and end of life care. Janice explains it's important to find a pathway which makes sense clinically but also improves the quality of care to patients and families. Janice addresses QI support too.

Olivia's point follows on from Janice, where she received a case study about a patient who was very sick and a long way from home. Throughout all her conversations, her main wish was to be at home with her family which she repeated numerous times. Seemingly they arranged for her to go back home to be with her family where she died a little later. Olivia highlights this is a perfect example of asking the patient what matters to you.

Sonia states it is not second nature for all clinicians to work in this way but we have to deal with this and make improvements. Sonia explains it is about individual person-centred personalised care and it is widely recognised that this is an equality issue too. Sonia highlights end of life care might be a good place to start as it is being reviewed across North West London both acute and in the community.

Linda agrees with Sonia points and states the interpreting improvement project demonstrated that many patients that do not speak English, do not understand their care, let alone can input into it.

	<p>Trish explains the lay partners would like to find a way to take this forward and make it a reality which we can evaluate and share with others as to why it is important. Trish explains Michelle is right to discuss whether there is a way we can do this and Bob has promised QI input if needed.</p> <p>Janice adds when putting the priorities forward it might be helpful to have an example to contextualise and set out the scope.</p> <p>Phayza suggests when discussing care plans with patients to take their cultures and beliefs into account.</p> <p>Trish thanks everyone for their support and moves onto end of year business planning.</p>	<p>Bob to follow up with QI support of 'what matters to you' at the right point of the project</p>
<p><b>6.</b></p>	<p><b>Strategic lay forum input into Trust business planning - Trish Longdon, chair, strategic lay forum</b></p>	
	<p>Linda circulated the business planning paper and questions whether it reflects what the lay partners are doing as there was a suggestion to present something smaller and concise.</p> <p>Trish requested to have the priorities set around the trust. Trish explains there would be three headings: person centeredness, integrated care and equity which lay partners continue to promote. The prospect of carrying what matters to you in a pilot format is something we support. In terms of integrated care, we were hoping to use the outpatients' programme to bring vision into this about what a referral into the outpatients would be. In terms of equity, we were interested in the 'did not attend' work and digital. Trish stresses the importance of having fewer items as this would make more of an impact.</p> <p>Sonia highlights digital inclusion and non-inclusion is important as this is an area the lay partners could make a real impact.</p> <p>Ed mentioned Raymond made a good point and an interesting push back in terms of where there is evidence and what we need to change. Ed explains what we have done is articulate the problem. Ed states we need to be clear on what the user insights are and use the evidence from Micelle's department to support this.</p> <p>Shanaka agrees with Ed. Often what Shanaka has found when presenting to the board is that we come with top level themes and then follow up with the detail. Shanaka feels it is perfectly reasonable to slice this into key areas we are focusing on and then provide a paragraph or two on why we are focusing on it. Secondly, Shanaka stresses not to deviate from what the focus is with NHS England and their improvements to patient quality and care. Shanaka believes we can sell our message if we illustrate these links as it shows we are supporting the overall quality improvement of the NHS.</p> <p>Trish thanks Shanaka for this suggestions.</p> <p>Jane explains although we have no control over costs, there maybe departments requesting for a budget and thus need influence. As a result, we could be an additional mechanism to promote why they need more money.</p>	

	<p>Trish concludes by saying the business planning paper will be condensed into three themes (person centeredness, integrated care and equity) and highlight within those our priorities.</p> <p>Linda questions whether to keep staff health and wellbeing and St Mary's Hospital redevelopment.</p> <p>Trish states there is agreement to keep this on and to circulate for everyone to review and comment.</p>	<p>Linda to circulate business planning paper for everyone to review and comment.</p>
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<b>7</b>	<b>Developing a user-insights function and establishing user-focused metrics - Michelle Dixon, director of engagement and experience</b>	
	<p>Michelle explains the ambition for the next workshop is to make it bigger, i.e. 80 people rather than 50 in order to get movement on this area of work, in particular ward pilots.</p>	
<b>8</b>	<b>AOB</b>	
	<p>Ed explains the majority of discussions have focused on digital whether it has been enabling or disabling. Digital has such strategic importance and Ed's worry is that we are at the beginning but there is a lot of quick wins which can be done. Ed states the lay partners should do anything they can to focus the trust's attention to this.</p> <p>Michelle explains there is not a standard operating process for getting an app out. As long as it passes the board and you met regulations you can create an app. Michelle explains the Trust are not complacent. The aim is to think carefully about how we resolve it.</p> <p>Shanaka suggest what is needed is an enterprise architecture which sets digital principles around the work you do which everyone refers to within the organisation. This is completed at a strategic level, capturing where you are now and looking at where you want to be and then setting principles around that. Shanaka suggests overlaying the person centred approach too.</p> <p>Michelle agrees with Shanaka's points and suggests a meeting to discuss this further.</p> <p>Trish thanks everyone for their support and asks whether everyone felt the hybrid approach was inclusive.</p> <p>Everyone is in agreement the hybrid approach worked well.</p> <p>Olivia states those with a freedom pass are unable to use it until 9am in the morning so to consider this when planning meetings.</p>	<p>Michelle and Shanaka to arrange a meeting to discuss enterprise architecture.</p>