NORTH LONDON PARTNERS in health and care

North Central London's sustainability and transformation partnership

NHS

Consultation on changes to planned orthopaedic care in north central London

Insight report on the views of transgender respondents to the consultation

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1. About this report

North London Partners in health and care is reviewing planned orthopaedic surgery for adults in Barnet, Camden, Enfield, Haringey and Islington, and as part of this review ran a 12-week public consultation on proposed changes to the service.

The future service proposes two partnerships for orthopaedic surgery, which have been formed by local NHS Trusts - UCLH working with Whittington Health, and the North Middlesex University Hospital (North Mid) working with the Royal Free London. These partnerships worked together to develop plans for about how services could be improved.

We believe that by organising services in a different way, we would be able to improve care and help more patients. The proposed changes could affect anyone who needs orthopaedic surgery in the future, who lives in our five boroughs or in a neighbouring area and has care in one of the hospitals involved in our proposals. Around 3,000 people could experience a change to where their surgery would take place in future, when compared to current arrangements.

When major changes to NHS services are proposed there are statutory requirements derived from the Equality Act 2010 to consider equalities and health inequalities.

For those commissioning or providing public services, there are two principle duties:

- Meet the Public Sector Equality Duty (PSED)
- To take account of the likely implications for changes to services or the location or access arrangements for groups or individuals protected under the Act.

To fulfil these requirements North London Partners in health and care (NLP) commissioned two independent pieces of work to examine the effects the changes might have on groups of people sharing protected characteristics. To examine the equalities dimensions of the proposed changes, NLP commissioned a three-stage equalities review:

Stage 1 was a desktop review, the output of which was a rapid scoping report which identified potentially impacted groups. It was used to inform pre-consultation engagement activities in the summer and autumn of 2018.

Stage 2 builds on Stage 1 and looks explicitly at the impact of the proposed model of care and the proposed location of services. The output, this report, delivers an initial HIEIA identifying positive and negative impacts resulting from the proposed changes and makes recommendations for the consultation stage; it also offers some initial thoughts on mitigations to reduce negative impacts.

There is a third stage which will take place after the consultation period and will build upon the previous two stages. It will deliver a revised and final integrated HIEIA, which will reflect the results of the public consultation. The report will offer an updated mitigations schedule and suggest next steps.

A separate, but linked, Travel and Access report considers the travel implications of the changes, which includes demographic profiling of local people who might be required to travel for planned orthopaedic surgery

Within the Stage 1 and Stage 2 reports of the equalities review, the gender reassignment protected characteristic (people who have completed gender reassignment and people who have not completed gender reassignment surgeries) was identified as being differentially or disproportionately impacted by the proposed changes, when compared with the general population.

This is because some research[1] suggests trans men (assigned female at birth) and trans women (assigned male at birth) and some non-binary people on HRT may be at risk of osteoporosis because:

- The need to take hormones that change the balance of oestrogen and testosterone in the body.
- After gender reassignment surgery, the level of hormones may decrease, and this may also affect bone density.
- The degree to which either of these factors affect the risk of breaking a bone, however, remains uncertain.
- Replacement sex hormones (testosterone for trans men and oestrogen for trans women) are necessary to maintain bone strength and are generally continued long-term.

This led to the need for the consultation exercise to make additional efforts to seek the views of those who have this protected characteristic to ensure that any future services are shaped to best address their needs.

2. Approach

A consultation planning sub-group was established, with representatives of the NLP comms and engagement network along with resident representatives who have supported the review to date. This group agreed a consultation plan with tactics to reach all of the groups identified in a stakeholder mapping exercise, which included those groups highlighted in the stage 1 and 2 HIEIA.

For the transgender protected characteristic the following tactics were agreed:

- Letters to medical and voluntary sector groups, advocating for trans-people inviting corporate responses
- Letters to medical and voluntary sector groups, advocating for trans-people requesting support in promoting the opportunity to respond
- Targeted conversations with contacts in local NHS Trusts working with the transgender community
- Targeted work in partnership with Gendered Intelligence[2]

[1] *National Osteoporosis Society (2014): Transsexual people and osteoporosis.*

[2] *Gendered Intelligence is a social enterprise based in Islington, working across the UK, whose mission is to increase understandings of gender diversity. http://genderedintelligence.co.uk*

3. Methodology

At the beginning of the consultation, letters were sent to groups representing or advocating for trans people.

In February 2020, Gendered Intelligence agreed to support the consultation through some outreach activities to promote the consultation within the trans community, via email and in-person.

- Emails were sent to the Gendered Intelligence mailing list
- A flyer was produced (see Appendix 1) for targeted distribution to a number of NHS clinics where trans people would be visiting. Copies of these flyers were distributed on several occasions by a Gendered Intelligence worker to 56 Dean Street (sexual health clinic) and a drop-in at the Tavistock Gender Identity Clinic

Under the guidance of Gendered Intelligence, a small incentive for participation (£25 Amazon voucher) was offered to those who were willing to take part in a structured telephone interview to give their views on the proposals. The flyer invited potential participants to contact a named person by email to schedule an interview.

Once contact was made, an initial email was sent to the potential participant explaining what was required and a link was included to a short animated film (2 minutes) that explained the proposals and a summary leaflet that gave a little more detail than the film. A time for a call was scheduled.

The telephone interviewer then called the person at the agreed time and a telephone interview was carried out. The structure of the interview mirrored the conversations which took place in all consultation meetings, and followed the same themes. It is worth noting that these conversations also followed the structure of the consultation questionnaire. The conversations explored:

- General responses to the proposals
- Whether they addressed the challenges laid out in the film and leaflet
- Views on patient experience and travel
- Views on pre-operative education, giving and receiving information
- The role of the care coordinator
- Impacts on specific equalities groups
- Additional equalities considerations in relation to harassment, discrimination, victimisation or prejudice
- Any other comments

The call concluded by gathering the demographic information that is requested from all participants.

4. Findings

Five interviews were completed over a two-week period. Interviews took place on the telephone at a time that convenient to the participant, with the majority taking place in the evening.

a. General responses to the proposals

All interviewees thought that the proposals were a good idea and the "practical action to solve a problem" was welcomed by one participant. Participants thought that offering a choice of two hospitals for inpatient surgery was adequate, with one participant noting that "having your clinical team stay with you" was a good thing and an important feature of the proposals.

One participant noted that it was better to have to travel further if it meant that your operation wouldn't be cancelled.

b. Do the proposals address the challenges?

All interviewees thought that the proposals would address the challenges set out in the consultation materials. Several mentioned that 'streamlining' was a good idea, as long as the communication was clear. The need for a patient's health records to be available at all sites was highlighted as a key requirement.

One participant thought it made sense for clinical teams to travel to different hospitals as long as they don't end up travelling during work time.

One participant had some concerns about whether it would address the growing demand, even if there was greater capacity in the two sites.

c. Views on patient experience and travel

For this group, the issue of travel was not a major concern. One participant commented that trans people were very used to travelling for healthcare as the specialties involved in gender reassignment were not available at many hospitals. One participant noted that there was a hospital for inpatient care at both ends of NCL so it does cover people regardless of where they live.

One participant noted that any inconvenience was outweighed by the lower risk of surgery being cancelled.

d. Views on pre-operative education, giving and receiving information

Participants were very open to different ways of giving and receiving information from the NHS in relation to orthopaedic surgery. The use of technology for this was welcomed and several participants mentioned that they already use secure online portals to access information and communicate with clinicians. They noted that it made things more convenient and less time consuming for both themselves and the clinicians in hospitals, although several participants added a note of caution that this wouldn't be as well received by everyone and that some might be less technologically literate than others.

For pre-operative education classes, almost all participants felt that face to face contact was important as people find it reassuring and also, if there were exercises involved, then it was important to ensure that people were doing them properly. However, if these classes were spread over several sessions then some of these could be offered via skype or similar services. The use of online films to help people remember exercises was also mentioned.

For follow ups there was a mix of preferences between face-to-face for "reassurance" for both patient and clinician, with some saying that a telephone or skype follow up would be fine if there were not obvious complications.

e. The role of the care coordinator

The care coordinator role was welcomed by all participants and there was a range of different ideas about how this role could make a difference to trans people. One suggestion was that a key element of their work was in relation to ensuring that information and appointments weren't lost. Another suggestion was specifically in relation to patients who suffer from anxiety, and that the coordinator could support them, offer reassurance and make the experience easier.

One participant said that the care coordinator would need to be adaptable and ensure that situations were looked at on an individual basis, and would need to be very good at solving problems. The NHS would probably need a team of people rather than just one person.

For this specific group, they saw the care coordinator's role as being important as an advocate for any trans people undergoing surgery. The insight offered was relevant not only to orthopaedics but also more widely in the NHS. It was felt that the coordinator could play an important role in:

- Ensuring that other team members understand the needs of individuals
- Asking patients their preferences in terms of pro-nouns used and ensuring that this was respected by the whole team;
- Supporting continuity of care and ensuring that sensitive information doesn't have to be repeated;
- Listening to concerns about gendered wards etc, reassuring that the most appropriate toilets are available in terms of patient's gender identity;
- Ensuring that staff understand people's toileting needs so that people get appropriate care – an advocate who is more aware than the rest of the team to pick up people's preferences;
- Offering trans-awareness to the wider team;
- Additional awareness of how key elements of care, such as catheterisation, might impact on those who have undergone gender reassignment surgery and that these also need to be discussed in advance of surgery

f. Impacts on specific equalities groups

There was a number of different groups highlighted by these participants as considerations for the different equalities groups highlighted under the public sector equality duty.

One of the key groups discussed by several of the participants was ensuring that the needs of trans-people were considered. The points raised included:

- For trans-people, acting in a sensitive manner and treating people with respect is important. Clinicians should keep information about patients confidential regardless of medical history or gender identity.
- It was important to recognise that not all trans people are the same and there is broad spectrum of people who identify as trans
- We also need to consider the gender of the ward that people are put into. For people who are non-binary they might want a private room where they don't have to identify as either male or female - people should be asked their personal preference.

As with other groups interviewed, travel and transport was a topic of conversation with the need to consider the following factors:

- Changes could affect those living in poverty, if travel support isn't offered
- For people with limited mobility, travel is a hurdle so we do need to think about how it will work for them.
- Those with learning disabilities might struggle when travelling on public transport.

Mitigations suggested included sending regular reminders and/or phone calls to make sure people remember where to go for different appointments and ensuring that clear information is available to people so that they can minimise the inconvenience or potential impact on income for themselves.

Other groups that were highlighted for consideration were:

- People that have experienced domestic violence or other stressful life-events could find it difficult to travel to new or different locations for their care
- Working people, including those who work shifts, could miss out on income if they have to attend appointments. It was noted that outpatient appointments weren't always flexible and didn't run to time so it was difficult for working people to juggle commitments. If they had to travel further for some appointments, this could become even more difficult

g. Additional equalities considerations in relation to harassment, discrimination, victimisation or prejudice

For this group, the main considerations were in relation to the location of services and whether trans people might feel unsafe when travelling to less central locations. There was also a desire that the NHS offer more training and development opportunities to staff focusing on trans-awareness so that staff competency in this area increases.

5. Demographics of participants

Local hospital	UCLH x 2	Barnet x 2	Outside NCL x 2	
Age	19 – 24 x 2	25 – 34 x 2	35 – 44 x 1	
Gender	Non-binary/male x 3	Male x 1	Female x 1	
Same as at birth?	No x 5			
Disability	No x 4	Yes x 1		
Ethnicity	White British x 3	Mixed white x 1	Mixed black x 1	
Religion	3 x no religion	1 x Atheist	1 x Christian	
Sexuality	Gay x 2	Straight x 1	Bisexual x 1	Queer x 1

6. Conclusions

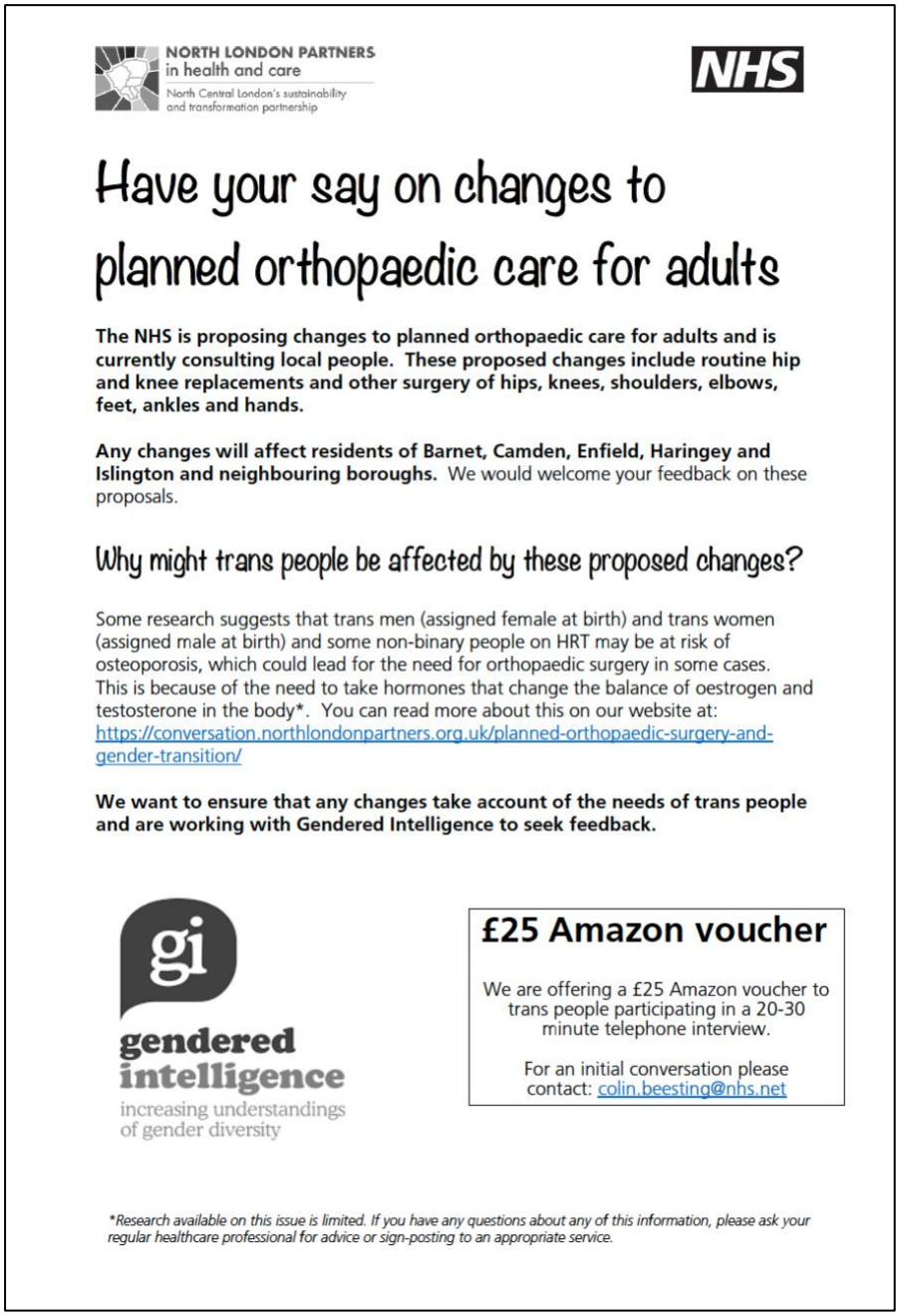
All interviewees were supportive of the proposals, several of them felt very strongly that they were a good idea and even with any disadvantage taken into account, that they should be implemented. The choice of two centres was welcomed, with several interviewees stating that they thought this was a strong mitigating factor for any travel inconvenience.

Like many other consultation participants, choice was the strongest message when it came to thinking about how patients would like to give or receive information to clinicians, with some welcoming the use of technology for this but others acknowledging that this wouldn't work well for everyone.

Specific insights offered in relation to the role of the care coordinator and the needs of specific groups in our community offered further considerations for implementation. When focusing on these two areas, the main insights offered were:

- There is a need for trans-awareness training across NHS staff to ensure that services are delivered in a way that recognises the specific needs of trans-people and gives staff the understanding, language and confidence to offer individualised services
- Trans people highly value interaction with staff who show an understanding of their needs and say that this enhances their overall experience and reduces anxiety. Sensitivity towards using appropriate language and the correct pronouns was a key element of this
- The care coordinator could play an important role as an advocate for trans-people throughout their care, ensuring that their preferences were explored, honoured and communicated sensitively to the wider team
- The need to consider the appropriate gender of wards in relation to people's identified gender was also very important. A particular element of this was the needs of non-binary people (who do not identify as male or female) and a consideration of private rooms with independent bathroom/toilet facilities
- Additional awareness of how key elements of care, such as catheterisation, might impact on those who have undergone gender reassignment surgery also needed to be discussed in advance of surgery

Appendix 1. Gendered Intelligence flyer



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NHS

Have your say on changes to planned orthopaedic care for adults

The NHS is proposing changes to planned orthopaedic care for adults and is currently consulting local people. These proposed changes include routine hip and knee replacements and other surgery of hips, knees, shoulders, elbows, feet, ankles and hands.

Any changes will affect residents of Barnet, Camden, Enfield, Haringey and Islington and neighbouring boroughs. We would welcome your feedback on these proposals.

Why might trans people be affected by these proposed changes?

Some research suggests that trans men (assigned female at birth) and trans women (assigned male at birth) and some non-binary people on HRT may be at risk of osteoporosis, which could lead for the need for orthopaedic surgery in some cases. This is because of the need to take hormones that change the balance of oestrogen and testosterone in the body*. You can read more about this on our website at: https://conversation.northlondonpartners.org.uk/planned-orthopaedic-surgery-and-gender-transition/

We want to ensure that any changes take account of the needs of trans people and are working with Gendered Intelligence to seek feedback.

gi
gendered intelligence
increasing understandings of gender diversity

£25 Amazon voucher

We are offering a £25 Amazon voucher to trans people participating in a 20-30 minute telephone interview.

For an initial conversation please contact: colin.beesting@nhs.net

Research available on this issue is limited. If you have any questions about any of this information, please ask your regular healthcare professional for advice or sign-posting to an appropriate service.