Consultation on changes to planned orthopaedic care in north central London

Insight report on carers

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1. EXECUTIVE SUMMARY

This report is part of a consultation undertaken by the North London Partners in health and care in relation to proposed changes to the organisation of planned orthopaedic surgery for adults in north central London.

Earlier work suggested that people who cared for others who had disabilities, health conditions or special needs (carers) should be included as a separate category during the public consultation, to ensure that their voices were heard, and their needs understood.

Fifteen people took part in telephone interviews in which they were asked about their lived experiences as carers, how they would manage, should they need planned orthopaedic surgery in the future and how the service could be shaped to help them. Participants also gave their general views on the planned changes.

In general, the changes were viewed positively, and were thought to be well thought through to meet future needs.

Carers identified difficulties they would face in attending outpatients' appointments and having day surgery or an overnight hospital stay. Those caring for adults had more barriers to considering their own health needs than those caring for children and young people, as they reported more difficulty in finding alternative carers.

Recommendations for consideration to ameliorate some of the carers' needs are:

- Offering carers the first appointment of the day
- Having a small number of fixed time appointments in each clinic
- Ensuring care co-ordinators are able to offer advice to carers about any help which might be available to them
- Care co-ordinators being able to offer support to ensure that carers can access any help which might be available to them

2. BACKGROUND

North London Partners in health and care (NLP) is proposing changes to the way in which planned orthopaedic surgery for adults is delivered. The changes will affect residents of Barnet, Camden, Enfield, Haringey and Islington, as well as small numbers of patients from other areas who travel to north central London (NCL) for orthopaedic surgery.

Details of the plans can be found on the NLP website[1].

When major changes to NHS services are proposed there are statutory requirements derived from the Equality Act 2010 to consider equalities and health inequalities. There are two principle duties on those commissioning or providing public services:

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

To fulfil these requirements NLP commissioned an independent three stage Health Inequalities and Equality Impact Assessment (HIEIA). The first two reports are available online[2] [3]. Stage three will follow in April and May 2020.

Substantial changes to NHS services are also subject to public consultation. The consultation took place between 13th January 2020 and 6th April 2020.

The stage 2 HIEIA recommended that during the consultation process the views of carers should be sought, as they were identified as a group for whom there could be some significant impacts. To facilitate this NLP commissioned Verve Communications Ltd to undertake a series of telephone interviews with carers to enable a better understanding of potential impacts and issues relating to the proposed changes and to ensure that the voices of carers were heard during the consultation process. Specifically, the research aimed to explore access issues based on lived experience and practical mitigations which might work for carers.

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[1] https://conversation.northlondonpartners.org.uk/orthopaedic-consultation-information/
[2] https://conversation.northlondonpartners.org.uk/wp-content/uploads/2020/01/NLP-EIA-scoping-v12.pdf
[3] https://conversation.northlondonpartners.org.uk/wp-content/uploads/2020/01/Verve-NLP-POSA-HIEIA-REPORT-DEC19-1.pdf

3. ABOUT VERVE

Verve Communications Ltd (Verve) is an independent full-service agency which supports NHS organisations in delivering transformation and change. Over the past several years Verve have supported NHS service configurations, institutional and major programmes of clinical change.

This document has been produced independently by Verve and represents our own analysis and advice.

We are grateful for the assistance and support provided by NLP colleagues, organisations supporting carers in north central London and to the carers who took part in interviews.

4. METHODOLOGY

NLP commissioned Verve to undertake fifteen interviews with carers across NCL. The aim of the interviews was to get a degree of insight into the lived experience of carers, the potential impacts on themselves and their families, if they needed planned orthopaedic surgery, and whether there were any mitigations which would help them should they need surgery.

4.1 FINDING PARTICIPANTS

Three paths to recruiting interviews were taken.

- The North London Partners orthopaedic review team asked local carers groups to promote the opportunity to participate in interviews, during outreach meetings
- Verve's specialist recruiter contacted support groups for carers across north central London and asked whether they could give our details to one or two carers who might be interested in being interviewed.
- The Residents' Health Panel established by NLP was utilised. See Appendix 1 for details.

Participants were recruited from each of these sources. Verve's specialist recruiter contacted people and explained why the research was being undertaken and what it would involve. A suitable time was arranged with those who wished to be interviewed and information about the proposed changes was sent via email; the information also contained URLs for the NLP website where more information was available for those who were interested.

4.2 CONDUCTING THE INTERVIEWS

A topic guide was used by the researcher to allow questioning which is responsive to issues arising whilst also ensuring that the same topics are covered in all interviews.

The interviews were conducted on the telephone and lasted between twenty minutes and an hour. They were recorded for the purposes of analysis.

4.3 CHARACTERISTICS OF THE INTERVIEWEES

The aim of the research was to gain insight from as broad a range of carers as possible within the confines of fifteen interviews. We were looking to have a spread of people across the five boroughs and to talk to people who cared for people in a range of age groups.

Our original intent was to talk to one or two young carers to consider, from their perspective, whether the proposed changes would impact on them. Whilst we recognise that young carers (under the age of 16) themselves would not be in the category of people needing planned orthopaedic care for adults, we felt their input could be valuable in terms of what might help them if the person they cared for should need such surgery. However, it proved challenging to recruit young carers for this project, given the time frames we were working to.

The participants fell into two categories – those who cared for adults and those who cared for children and young people:

Borough	Caring for adults	Caring for children/young people
Barnet	3	1
Camden	2	0
Enfield	2	1
Haringey	2	1
Islington	2	1
Total	**11**	**4**

Those caring for adults were caring for partners, parents, adult children and in one case a friend. Those caring for children/young people were all parents caring for their own children. The people being cared for had a range of disabilities and health conditions, including autism, mental health problems, Alzheimer's and physical disabilities. Some of the carers had health needs themselves.

5. FINDINGS

All participants were sent an information sheet setting out the proposed changes, and given URLs to follow through, should they wish to read more information on the NLP website. The early part of the interview was designed to mirror the conversations the NLP team had had in consultation meetings across north central London, that is to gather views on the proposals, including:

- People's thoughts on whether the proposals address the challenges
- Views on patient experience and travel
- Views on pre-operative education, and the giving and receiving of information
- The role of the care co-ordinator

Of the fifteen people interviewed only one had read the information ahead of the researcher calling them. To compensate for this, the researcher explained the nature of the proposed changes and the drivers for change prior to commencing the interview. The views expressed were as follows:

5.1 GENERAL RESPONSES TO THE PROPOSALS

With one exception people thought that the proposals were a good idea and would rationalise the delivery of planned orthopaedic surgery for adults across NCL. The exception was a person who queried whether it was a money saving exercise and described herself as cynical about changes of this sort.

Participants said that they would be willing to travel a little further for good care, especially if they could be assured that their operation would not be cancelled.

5.2 DO THE PROPOSALS MEET THE CHALLENGES?

When the proposals and the challenges were explained to them most people thought that some reorganisation was necessary, and the proposals sounded good and sensible ways to do that.

5.3 VIEWS ON PATIENT EXPERIENCE AND TRAVEL

The carers were used to travelling to different hospitals, with the people they cared for and sometimes for themselves. For those using public transport some hospitals were easier to reach than others, depending on where people lived. For those with cars there was less worry about visiting different hospitals as long as there was adequate parking. Generally, the issue raised by carers was not the distance to travel but the time it would take, as some participants could only be away from their caring responsibilities for short periods of time.

5.4 VIEWS ON PRE-OPERATIVE EDUCATION AND THE GIVING AND RECEIVING OF INFORMATION

For those who were comfortable with technology, different methods of giving and receiving information were welcomed, as this was assumed to mean that there would be fewer appointments needed at hospitals. However, there were people who might struggle with online methods, but those people were open to having telephone conversations.

5.5 THE ROLE OF THE CARE CO-ORDINATOR

The care co-ordinator role was welcomed by all participants. Generally, carers felt that their needs can easily be overlooked, and that having a named person with whom they could discuss their needs was a very good idea. It was hoped that care co-ordinators would be able to help carers navigate the system.

5.6 OTHER FINDINGS RELATING TO CARERS

The responses to how people would manage if they needed planned orthopaedic surgery ranged from “It wouldn’t be a problem, my partner would step in” to “It couldn’t happen, I cannot leave my partner for more than an hour or two at most. There is no-one I can turn to for help”.

One important consideration was the amount of time spent waiting in outpatients – long waiting times put people off going for appointments, as they could not plan adequately for unspecified times away from home. One mother, for example, said that appointments for her would have to be between school runs, as her child with autism would not be able to tolerate someone else taking him to, or picking him up from, school. A woman caring for her husband, who had dementia, said she had to call him every half hour or so to tell him where she was – but he became distressed if she could not tell him how much longer she would be away from home.

Some carers had considered taking the person they cared for to outpatient appointments, but generally this was difficult as the people being cared for could become distressed at being away from home and waiting for long periods of time.

For many of the participants the thought of needing an operation, whether as a day patient or with an overnight stay, was very worrying and they had no idea how they would cope should the situation arise. Some of those caring for adults said that it would be difficult or impossible to find adequate alternative care; for others there were people who might step in to help, but the people they cared for would be distressed by the changes to their routine. Again, for most of those caring for children and young people family members were likely to be able to step in or, in some cases, more formal respite care was a possibility.

Planning was an important factor for all the carers when thinking about their own health needs. They said they needed time to think about their options and, where possible, to make alternative care arrangements.

Having online or telephone appointments was an attractive idea for carers, as they would not have to leave home to speak to a medical professional. Some had already experienced this with other health disciplines and thought they generally worked well for follow up appointments.

6. CONCLUSIONS

For many carers, especially those caring for adults, their own health needs were secondary to those of the cared for person. When asked how they would manage having planned orthopaedic care some could not envision how they would be able to accommodate this, as they said there was no possible alternative care.

Having someone to discuss options with, such as a care co-ordinator, would be important for carers, so they are fully aware of all implications of having planned orthopaedic surgery, such as timings of appointments, recovery times, restrictions on movement etc. It would also be useful to carers to be able to discuss their needs, and those of the people they care for, so that they could be fully aware of any help that might be available to them.

6.1 RECOMMENDATIONS FOR CONSIDERATION

6.1.1 OUTPATIENT APPOINTMENTS

Long waiting times in outpatients was often mentioned by carers as being stressful. Some had had to leave without seeing a medical practitioner because they felt they had been away from home for too long. Carers suggested some ideas which would help them when they needed outpatients' appointments which we recommend NLP considers:

- **Offering first appointments of the day**
  For some people having the first appointment of the day, or clinic session, would usually mean a shorter wait, as no backlog of patients would have built up. This would not work for everyone, however, as some people would prefer an appointment later in the day.
- **Offering a fixed time appointment**
  Having a small number of fixed time appointments in any clinic, available to carers and others who had similar needs. It was suggested that a scheme like this would mean that, for instance, a 3pm fixed time appointment would be seen as near to 3pm as possible, regardless of people who had earlier appointment times who were still waiting.

6.1.2 CARE CO-ORDINATORS

The care co-ordinators could be a vital link to carers, if they are able to advise them on what help would be available to them. We recommend:

- **Advice**
  Care co-ordinators should be aware of any help which is available to carers who need elective orthopaedic surgery.
- **Help**
  The role should go further than signposting carers to help, as some of them require assistance in negotiating systems and applying for any help with would be available to them.

7. APPENDIX 1- THE RESIDENTS' HEALTH PANEL

North London Partners in health and care established a Residents' Health Panel with the aim of involving a diverse group of local residents in the planning of health and care services in the future. The panel aims to be broadly representative of the local community and comprises approximately 800 residents, who were recruited in Autumn 2019 using street-recruitment methodology.

The Residents' Health Panel is stored on a database which can be filtered based on demographic and socio-economic information given by panel members at the point of recruitment.

For this element of the consultation process the database was filtered for those who had said they were carers.

An email was sent from NLP on 18th February 2020 to all those who identified as carers informing them that a researcher would be contacting a selection of panel members in the coming days to gain feedback on how proposed changes might affect them, and giving details of how to opt out if they did not want to be contacted in this way. No opt outs were received by NLP.

The database of carers contained 115 names and yielded 65 people who had email addresses and telephone numbers, and so were potential interviewees.

It became apparent when the recruiter started to contact people that some had defined as being a 'carer' within a wider scope of the definition than was required by this study – with some being paid carers and others being parents of children or young people.

Those who were not caring for people with disabilities and/or health conditions were thanked for their time but were not included as interviewees.