Report from CCG patient and public consultation event Wednesday 22 March 2017, hosted by Healthwatch Enfield at Community House in Edmonton, focusing on proposed changes to clinical criteria for NHS treatment.

Background
Healthwatch Enfield was approached by NHS Enfield Clinical Commissioning Group to organise and promote a public engagement event on the proposed changes to clinical criteria. This formed part of the consultation process for the NHS Enfield Clinical Commissioning Group's review of **"Procedures of Limited Clinical Effectiveness" (PoLCE), which may see patients being unable to access some treatments currently available on the NHS.**

Information contained within this document provides on overview of conversations held on the day, feedback from attendees and points for further consideration by NHS Enfield Clinical Commissioning Group.

Contributions and questions

Comment / question	Response (if any)
Impact on individuals	
Using the Glasgow hearing aid profile, 96% people who have mild hearing loss, 12 months on have gained benefits from having a hearing aid fitted. If you have hearing loss over a certain age, it can increase your risk of dementia so having a hearing aid fitted will decrease the risk.	Dr Mahmoodi invited representatives from Action for Hearing Loss and other professionals in the room to submit their evidence to the CCG
Prevention and early diagnosis of hearing loss can also prevent mental health issues, isolation. If we are turning people away because the hearing loss is mild it will be years before they approach us again (usually after 10 years). Research suggests the earlier a person is diagnosed and fitted with a hearing aid the less impact the loss has on their life.	Dr Mahmoodi invited representatives from Action for Hearing Loss and other professionals in the room to submit their evidence to the CCG
There is only one Clinical Commissioning Group that has actually implemented changes to the hearing aid criteria. Getting a hearing aid fitted after early diagnosis helps with long-term health and wellbeing. If this didn't happen, it will cost the Clinical Commissioning Group more in the long term.	Dr Mahmoodi invited representatives from Action for Hearing Loss and other professionals in the room to submit their evidence to the CCG

Comment / question	Response (if any)
Under the proposals, anyone who currently has a hearing aid, but does not meet the revised criteria, will not be able to have their hearing aid replaced once it wears out. This will have a very negative effect on the wellbeing of these patients. Regardless of the outcome of this consultation, the very fact that these proposals are being considered is causing stress to people who currently have the benefit of a hearing aid.	No response provided
We have been very worried by reports in the media that at least one CCG is actively considering refusing knee replacements unless the patient concerned "is in so much pain that they cannot sleep at night".	Dr Mahmoodi explained that he was not seeking to justify or to elaborate on the proposed changes to criteria for certain NHS treatments; the consultation event was focused on the process.
Enfield CCG's proposed threshold appears to be extremely high, as the consultation document refers to "patients whose pain is so severe and/or mobility is compromised that they are in immediate danger of losing their independence and that joint replacement would relieve this". This threshold is not in line with NICE guidelines.	Dr Mahmoodi stressed that the purpose of the consultation is to listen to feedback not to discuss the criteria proposed
The Equality Impact Assessment is inadequate. For each of the protected groups (i.e. those protected by the Equality Act because of specific characteristics such as age, ethnicity, religion etc.) the entry in the column headed "Nature of potential impact (positive/negative/unknown) is "Unknown". In other words, no actual impact assessment, even on a provisional basis, has been attempted. It means that people responding to the consultation do not have the full information they need to make a judgement as to whether the proposals are fair and equitable, and whether any sections of the community will be adversely affected to a greater degree than the general population.	Mark Eaton, Transformation Director stated that NHS Enfield Clinical Commissioning Group is unable to carry out a full Equality Impact Assessment of the proposed changes until decisions have been made.

Comment / question	Response (if any)
Key areas of possible concern are where pain killers would have to be relied on in lieu of an operation – e.g. bunions in particular, where it is very clear that people would instead be reliant on pain killers, and possibly also the case with knee replacement too? Presumably there is a health trade-off between the long-term risks of constantly taking pain killers, and the risks posed by having an operation? This isn't clearly referenced, but perhaps should be, to ensure that a patient is not exposed to greater risks from pain killers than would have been posed by an operation?	Participant's feedback submitted in writing due to time constraints hence to response could have been provided
Further, the more pain one is in, the harder it is to mobilise and take exercise, so the condition is presumably likely to get worse, as is the patient's general health and wellbeing, but no reference is made to this risk or how to weigh it among the factors under consideration.	Participant's feedback submitted in writing due to time constraints hence to response could have been provided
*There is no reference to the potential **mental health** impact of having to live in constant pain, and the likely resulting depression etc., that may then entail further medication being taken and/or additional treatment. Making no reference to this at all suggests that it is not being taken into account. This therefore seems to fail to treat mental health on a par with physical health, as required by the Parity of Esteem policy.*	Participant's feedback submitted in writing due to time constraints hence to response could have been provided
Providing person-centred care	
The CCG had refused me a certain treatment recommended by my GP, and this had resulted eventually in much greater cost to the health service.	No response provided
This proposal reminds me of the endless assessments disabled people have to endure in order to claim disability benefits, where they constantly have to demonstrate that they are "disabled enough" to merit support.	No response provided

Comment / question	Response (if any)
The judgement of individual clinicians, based on their knowledge of the patient concerned, will be trumped by the more impersonal criteria imposed by the CCG. I had a consultation with my clinician, who had referred me to the hospital for a particular treatment; the hospital had then declined to provide the treatment as they said I did not meet the eligibility criteria. I made a big fuss and challenged the CCG's decision.	Dr Mahmoodi stressed that decisions with regard to treatments for individual patients would still be made after a personal consultation in which the clinician would explain the options available, and the risks and benefits associated with each, for that particular patient.
Accessibility of consultation	
The consultation questionnaire is too difficult for lay members to understand; please try and make it "easy friendly language"	Participant's feedback submitted in writing due to time constraints hence to response could have been provided
Approach to consultation	
It is hard to understand how a consultation could be just about process. The examples given by the Medical Director about how someone with no pain etc. would not receive, for example, a knee operation, were extreme, since that does not seem to happen currently anyway; I still have no feel for where the proposed new thresholds are and the impact they could have.	Dr Mahmoodi gave some examples to demonstrate that in many cases, the proposed new criteria would mean that patients who were not experiencing pain or discomfort would not be eligible for treatment for the conditions on the list, whereas those who were experiencing pain and discomfort which was clinically significant would still be eligible. One example was that of a small hernia, which the patient was completely unaware of because there were no symptoms, which had been discovered during an investigation for a different condition. In the past, this patient might have been referred for a hernia operation, but under the proposed changes, they would not.
It seems to me that the 'evidence' itself being contested, meaning that there is therefore no straightforward link between the 'evidence base' asserted and any policy decisions that Enfield CCG might make.	Dr Mahmoodi assured the meeting that the CCG made every effort to weigh up all the available evidence and arrive at a judgement in the best interests of local people. He also stated that the proposals were all in keeping with guidance from NICE (the National Institute for Health and Care Excellence).

Comment / question	Response (if any)
It sounds as though the NHS Enfield Clinical Commissioning Group is taking no responsibility for the proposals it sent out for consultation in its own name! Although it is right that the NHS Enfield Clinical Commissioning Group is open to feedback, it is very strange that it cannot explain why some of the thresholds are framed as they are. Why propose them at all if you can't even explain why they are there at all? There was also much emphasis on NICE guidance, but NHS Enfield Clinical Commissioning Group is already NOT complying with all NICE guidance e.g. IVF policy.	Participant's feedback submitted in writing due to time constraints hence to response could have been provided
Although this consultation event and other NHS Enfield Clinical Commissioning Group messages about the changes to criteria for NHS treatments talk about Camden, Haringey, Islington, Barnet and Enfield going to be having a common policy on these procedures, it seemed clear from the meeting that it is quite possible that each borough may come to quite ***different*** *positions on the same 'evidence base'. I therefore find the Clinical Commissioning Group's position really rather disingenuous. NHS Enfield Clinical Commissioning Group's communications regarding whether or not the proposed changes will form a common policy across the boroughs, is misleading. Giving a false impression about whether or not a policy will apply just in Enfield, or across five boroughs together, is a not a sound basis on which people can respond to proposals.*	Participant's feedback submitted in writing due to time constraints hence to response could have been provided
I felt the speaker dodged and did not answer questions. He was very contradictory and at times answered with one word answers and did not want to elaborate. When asked about evidence, he was very defensive.	Participant's feedback submitted in writing due to time constraints hence to response could have been provided
Speaker didn't answer all questions clearly and contradicted himself at times.	Participant's feedback submitted in writing due to time constraints hence to response could have been provided
Alternative proposals	

Comment / question	Response (if any)
Is NHS Enfield Clinical Commissioning Group looking at other ways of cutting costs e.g. through redesigning pathways?	Dr Mahmoodi confirmed that this consultation exercise is only one part of the concerted effort by the CCG to improve services while reducing costs, and that other measures including redesigning care pathways are also being implemented.

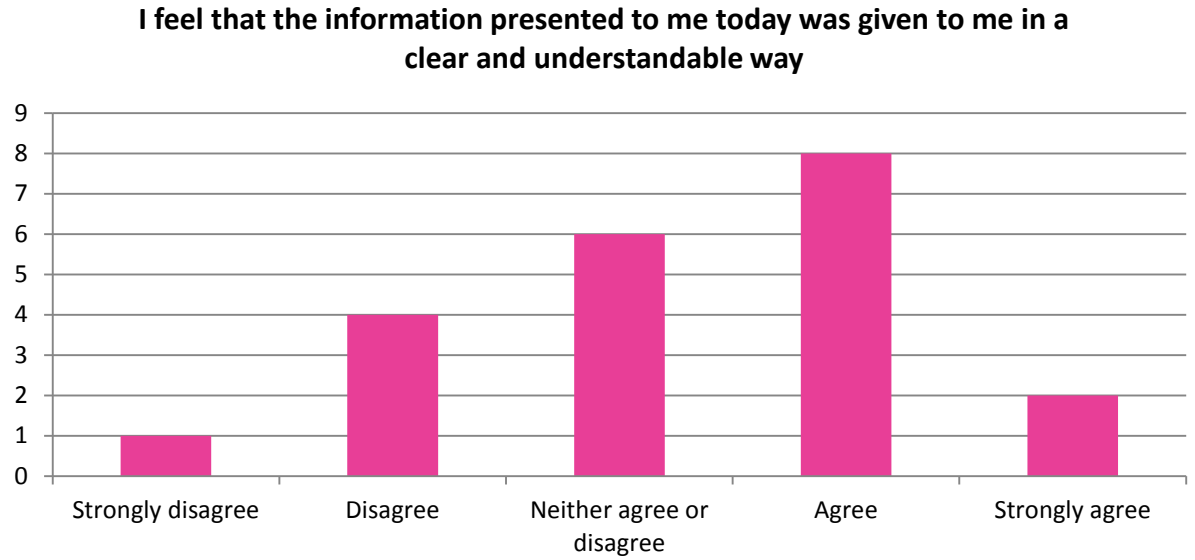
Questions submitted by participants for consideration by NHS Enfield Clinical Commissioning Group at the event (due to time constraints)

The following questions have been combined from individuals present at the event.

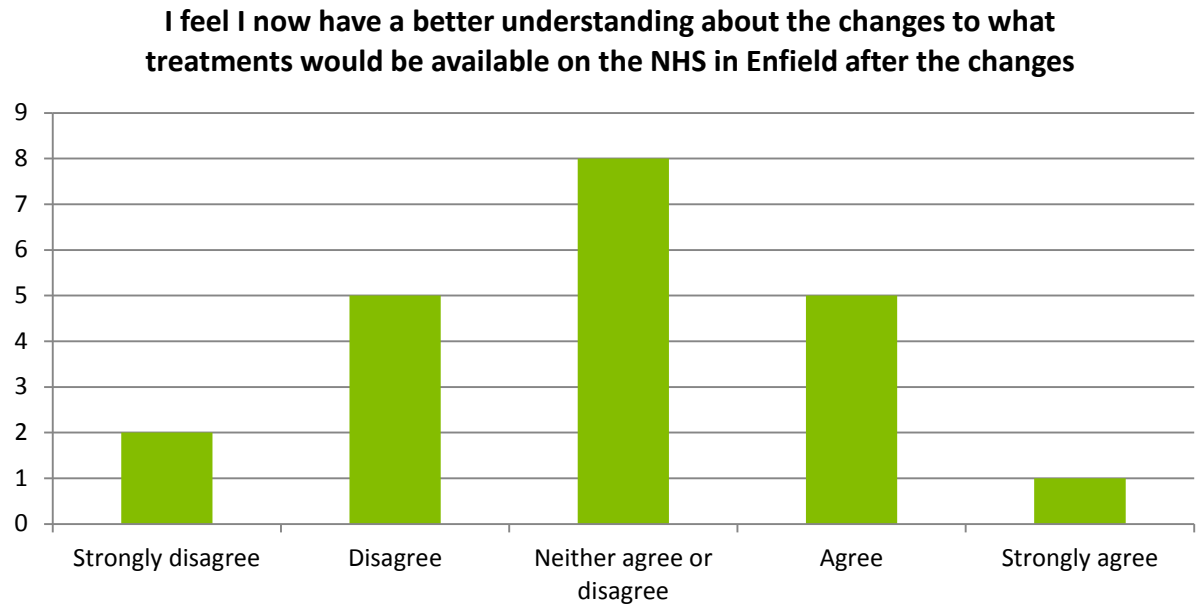
- On page 8, NHS Enfield Clinical Commissioning Group's document references "pre-engagement work". Can you give examples, please?
- I would have expected some mention of how patients with learning difficulties would manage to navigate/have to know how, to demand/negotiate to get the treatment they need. With the cuts in social services what are the chances of "them" failing to be treated well, get the best clinical service. Poorer communities would also find the route to best treatment blocked by red tape and bureaucrats.
- How is it correct to make smoking cessation a requirement before accessing a service?
- What is NHS Enfield Clinical Commissioning Group doing to involve our non-English speaking communities i.e. in Edmonton Green, Turkish, Somali, Bengali and other east European living and working in Enfield?

Effectiveness of the event
34 people attended the session and 21 attendees completed a feedback form.

Of the individuals who completed a feedback form, **48% agreed or strongly agreed** that the information presented to them by NHS Enfield Clinical Commissioning Group at the consultation event was given to them in a clear and understandable way. Over **52% of individuals did not rate the information as accessible**.



Only 29% of attendees agreed or strongly agreed that following the event, they had a better understanding about the changes to what treatments would be available on the NHS in Enfield. **71% of individuals** disagreed, strongly disagreed and neither agreed nor disagreed.



Monitoring form:

- 3 were male and 11 were female
- 8 were aged 40-64 and 7 aged 65+
- 6 were British, 3 were Indian, 2 were Caribbean, 1 was Irish and 1 was Chinese
- 4 classed themselves as having a disability
- 3 attendees were from wards within the South of Enfield (e.g. Edmonton Green and Upper Edmonton), 3 attendees were from wards within the West of Enfield (e.g. Winchmore Hill, Southgate and Bush Hill Park), 1 attendee was from the East of Enfield (Ponders End) and 3 attendees were from wards within the Centre of Enfield (e.g. Bush Hill Park and Southbury)

4 individuals in attendance were representing organisations that work with people with hearing loss.