

## Clinical genomics service specification consultation

Healthwatch Birmingham welcomes the opportunity to respond to NHS England's Clinical genomics service specification consultation. Our key role is to make sure that patients, the public, service users, and carers (PPSuC) are at the heart of service improvement in health and social care. In line with our role, we have focused our comments on:

- Patient and Public Involvement and engagement
- Whether the proposal is responsive to the needs of the people of Birmingham

Healthwatch Birmingham notes that the opportunity to respond to the consultation was originally available for a month but has been extended twice to allow more views to be shared. As this period has also covered the death of the Queen and a period of national mourning, we welcome the consultation being extended. However, we would like to note that a longer period of consultation would be considered best practice.

We note that an email address and telephone number have been made available for members of the public, such as those without digital access, to share their views more widely just than the survey.

Healthwatch Birmingham are pleased to see the clear and extensive documentation shared as part of the consultation. This allows PPSuC to have access to information and give clear informed views on the proposed changes. We particularly welcome the inclusion of the stakeholder testing engagement report, as this clearly lays out the engagement work that has been undertaken as part of developing the specification, and the responsiveness to suggested changes as part of this work. This reassures the public that their views will be taken into consideration and changes made as a result where appropriate.

The inclusion of easy read documentation is to be noted, as it allows further engagement with the consultation. We also note public webinars were held as another alternative method of engagement. Enclosing the previous service specification alongside the proposed specification is also to be commended for its transparency, allowing full understanding and oversight by the public.

## Proposal

Healthwatch Birmingham welcomes the focus on equity of access throughout the service specification.



Birmingham has one of the highest populations with more than 1.2 million residents. There are over a hundred different languages spoken in Birmingham. Some areas of the city are mainly (at least 80%) populated by residents from Black, Asian and Minority Ethnic groups. More than half of Birmingham's population is under the age of thirty. Forty-six percent of Birmingham's population live in the 10% of most deprived areas in England, which accounts for some very poor health outcomes. The city has a level of homelessness that is more than three times the national average, long-term unemployment two and a half times higher, and one in three children live in poverty. One in four people live with a mental health condition that started in childhood. There is a prosperity gap of 10 years between the most affluent and least affluent people living in Birmingham.

As part of ensuring equity of access, existing data sources should be utilised to examine the demographic profiles of local populations and compare this with the demographic profiles of existing patients using the clinical genomics service. Where gaps are identified, these populations should be a priority to engage with as the proposed service develops and is implemented.

We welcome that the proposal allows patients to have continuity of care in who they see, and the number of times they need to repeat their 'story' to. We frequently hear how this is a frustration for patients.

*"We never saw the same doctor twice and were told something different each time"*

*"Each time I had to repeat my symptoms and what had happened which was very traumatic"*

*"It seems that as a patient we have to explain our diagnosis and explain everything from the beginning when have ended up in A&E or to my doctors."*

Widening access to clinical genomic services as proposed should allow for faster diagnosis. People tell us about the problems they experience when trying to obtain a diagnosis for their conditions.

*"I would like to give my painful story to diagnosis as I feel people should know what is happening and the misery we are having to go through without any real specialist help."*

*"I have been suffering for the past few months and there is still no diagnosis. I was referred by my GP and they keep saying blood is clear. I am a single mother and have no help at home and I am in pain"*

*"A patient for over 10 years and still being treated for symptoms, no diagnosis."*

*"The parents feel as though they were not informed adequately during this period of time, and that they still do not have any official diagnosis. They also feel as though they had to regularly track down doctors to get information regarding results and scans."*



*"Nearly 3 years I have been waiting for a diagnosis for my 10 year old daughter, she struggles daily which is hugely affecting her mental health and education."*

People in Birmingham tell us about their frustrations about long waits for appointments, though there is a lot of understanding about the backlogs in services due to the pandemic. Clear communication about proposals being implemented to allow patients to access the care they need sooner would be welcomed by the public, as a clear demonstration of taking their concerns seriously.

As changes are implemented, clear communication will be needed with public to ensure they have trust in the quality of service they are receiving. Explaining the procedures in place to ensure workforce competency and service provision capacity will be key for the public to have confidence in the changes.

We look forward to hearing more about this work as this develops. We look forward to seeing in the consultation report how the proposals are amended in response to feedback.

We are keen to see in the Commissioning Implementation Plan how patient feedback will be used as a tool to monitor how patients are experiencing the changes and that the proposals have led to the expected improvements.

Yours Sincerely,



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