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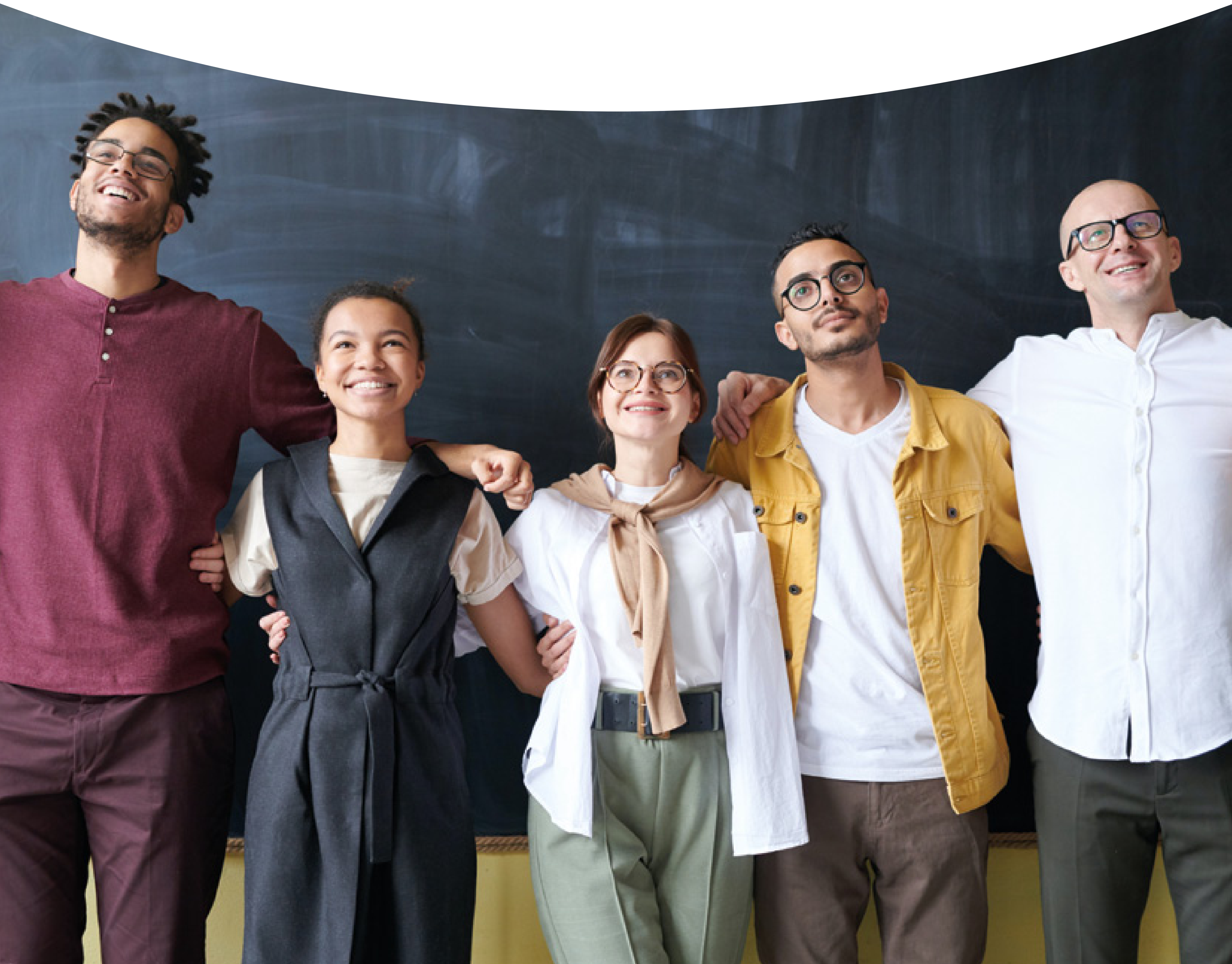
NHS
Central London
Community Healthcare
NHS Trust

Engaging with under-represented populations with diabetes



What needed to change?

A discrepancy between the number of people with diabetes and the number accessing available services was highlighted in Central London Community Healthcare (CLCH) activity data. It was also recognised that there is an increased risk factor for diabetes for those of certain ethnic minorities. The health equalities team within CLCH set out to engage with underrepresented populations with diabetes to understand the possible reasons for this discrepancy. The group focussed on engaging with Black African, Black Caribbean and Pakistani populations as these were the groups known to be underrepresented in accessing diabetes services. A co-production approach was used to allow the community voice to be heard as many NHS services are based on commissioning models that could inadvertently exclude certain ethnic populations.

> **“I wanted the community voice to feed into the healthcare we provide.”**
> (Staff member, Interview)

Engaging people with lived experience of diabetes

Recruitment

Messages were shared via a number of CLCH communication channels, via the diabetes nurses and using posters to advertise the co-production project and invite people to the steering group. The group consisted of five people with a direct lived experience of diabetes and a further two who had an indirect experience (caring for someone with diabetes or living in close proximity to someone with diabetes).

Gathering Ideas

A web-based tool, Slido, was used to allow everyone to contribute their ideas and to collate responses in real-time. The initial question asked to the group was **‘Why do we think we see under-representation of certain ethnic groups within diabetes services?’**. Seven themes were highlighted that were thought to contribute to the discrepancy between the number of people with diabetes and those accessing services:

- Decisions to seek help
- Reduced access to doctor / GP appointments
- Inconsistent application of Always Events®
- Usage of complementary and alternative medicine
- General knowledge of diabetes
- Self-management of diabetes
- Knowledge of diabetes services

An open, online survey was developed based on these themes.

> **“If this project was done with a room full of suits just presupposing what the issue is, we would be nowhere near where we are right now.”**
> (Staff member, Interview)

Surveying people living with diabetes

The survey aimed to gather information on how people access medical care in general and for their diabetes; when they would seek medical advice and how, along with any aspects of seeking care that would be challenging to them. The aim was to look at how people interacted with healthcare services by age, gender and ethnicity.

The survey was in field between October 2021 and January 2022 and it gathered 186 responses. The data were analysed and the group identified any differences between age, gender and ethnicity of respondents and how different ethnic groups were interacting with healthcare services.

Findings

Initial survey findings indicated that there was a knowledge gap between ethnic groups. The white British ethnic groups tended to know more about the services a GP could provide for people with diabetes, in comparison to the ethnic groups that it most affected. When deciding whether to seek help, over two thirds of survey respondents reported that consulting their GP was not the initial action taken when a health issue is suspected. Over a third of the Black Caribbean respondents (36%) reported that their initial action would be to self-medicate, while 44% of Pakistani respondents would consult knowledgeable members of their family.

Progress so far

- Co-production steering group was set up to oversee the work and regularly meet online to discuss the project.
- Links have been made with third sector and voluntary organisations, such as Diabetes UK, and a diabetes club held in a local church. They provide connections to community partners and insight into diabetes awareness and service access. The Somali Women’s Empowerment Organisation and Harrow Diabetes Community Club provide links to people with lived experience, who the group engaged with via interviews and focus groups.
- People with lived experience on the steering group have been involved in developing the survey, analysing the results and writing a report on the findings.

> **“(I) definitely feel equal. I could say something that (staff member) probably isn’t sure of, never heard of, or didn’t come across in his mind and I could explain it because I know it. That’s not being big-headed about it, I’ve lived for nearly 50 years with diabetes so I want to believe that I know what I’m speaking about.”** (Person with lived experience, Interview)

- The findings from the survey provide valuable insight into the reasons why people from particular ethnic groups have difficulty accessing NHS healthcare services. It is hoped these findings will be of interest to staff working in primary and secondary care. For this project specifically, the data from those who identified as having diabetes and from one of the minority ethnic groups specified, will be used to identify next steps within the co-production project.
- A short film has been produced, sharing the experiences of people with lived experience and the challenges they face in accessing NHS healthcare services. This has been shared on YouTube.

Key Challenges

Recruitment. With the time pressures on the project, insufficient time was allocated to really focus on reaching out to the target groups.

Engagement. The steering group reduced in size, and it was felt that this was due to the time commitment required. Additionally, it was felt that due to the stigma around having diabetes, people were reluctant to come forward. As the steering group only had a few people with lived experience, the group was potentially not representing the voices of those most affected by diabetes.

Opting for a virtual approach. All meetings were held virtually due to Covid-19 restrictions. Although this offered greater flexibility, it was difficult to get conversations flowing.

Survey accessibility. With more time and funding, the survey could have been translated into different languages to make it more accessible.

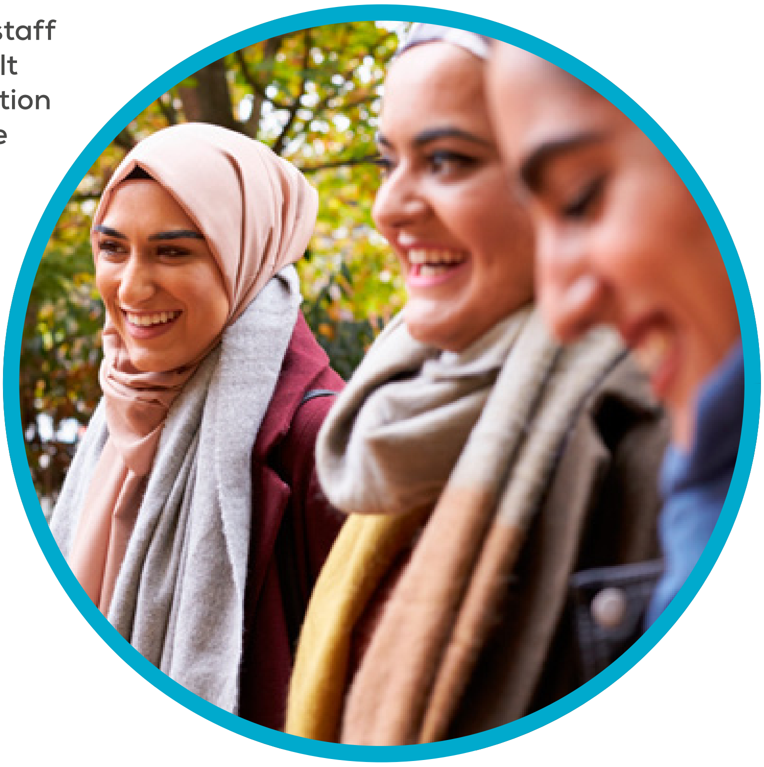
Trying to get consensus. When a co-production approach is used there are many views to consider and it can be challenging to reach a consensus.

Staff engagement. Feedback from staff has been mixed and it can be difficult to engage clinical staff in co-production due to their time constraints and the requirement for a shift in thinking.

People with lived experience felt equal partners with healthcare professionals.

Next steps

The steering group will discuss the key findings from the engagement work. The information from the survey and qualitative work will be used to help co-produce an intervention to improve access to diabetes services for Black African, Black Caribbean and Pakistani populations.



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