

Integration Index - Health and Care

Experience Profile #2 - Engagement Report

A person of South Asian ethnicity with diabetes.

Introduction - The Integration Index Project

The overall objective is for Healthwatch to develop a qualitative research methodology for local health and care systems to help them assess how well they are doing at providing joined up care.

As part of this work Healthwatch Cambridgeshire and Peterborough were asked to research the health and care experience profiles - A person of South Asian ethnicity with diabetes. (Please find attached)

Health and social care services should be able to offer whole-person care which allows early identification of disease, timely and appropriate interventions, and prompt management of complications.

There are several barriers to effective diabetes management within the South Asian population. These include aspects of patients' self-care as well as clinical management of the condition.

The sample in our research shows that patient involvement in establishing an integrated service is essential. The lived experiences will help planning and produce care that reaches people in their community, so that they can improve day-to-day physical and mental health and reduce health inequalities.

We recently ran engagement sessions for people from a South Asian background living with diabetes. We arranged one-to-one interviews by phone and Zoom and spoke to eight participants. Seven had used local Primary Care services only and one recently used Secondary Care.

Demographic data.



The breakdown below describes the demography of the people we spoke to.

- 7 x Peterborough and 1 x E. Cambs.
- 1x prediabetic, 6x type two, 1x type one.
- Male 5. Female 3.

Age. 25-34: 2

35-44: 3

45-54: 3

65-75: 1

Findings/Themes

All participants said they received reminders for the annual NICE recommended 9 key care processes check in a timely way. The appointments are continuing at surgeries throughout the Covid-19 pandemic.

However, participants tell us these only cover clinical issues. There was no offer of support through integrated services such as podiatry, mental health, dietary, stop smoking or exercise groups. No printed literature was provided.

Seven participants said they wanted updated information about their diet and activity as they had no reliable information since diagnosis.

Seven were concerned about weight gain since the Covid pandemic and that they did not know how to get help with this. Three were especially frustrated with only being able to walk in their local area.

Seven said they would find a locally produced NHS app to log and share their self-tests with surgeries helpful. They also said this could be a good opportunity to find information about diet and other local integrated services. However, it needed to be easy to use and three said they would like to have video style information rather than text. This was due to literacy skills and eyesight issues. An app however should not replace face to face advice from providers.

Six said they would like to be part of an online peer support group; it would open a social outlook as well as offer advice and lived experiences from the same cultural values. Three also mentioned a support group within their local community would be helpful when face to face meetings are allowed.

Two from this group said after Covid restrictions a face-to-face local peer group would be beneficial to this community as they would relate better due to different cultural values and languages.

Four were offered educational courses upon diagnosis, which were thought to be culturally sensitive. There were no interpretation services required in this particular group. However, two participants said family members who carry out



the shopping and cooking could also be invited to attend as they needed to be aware of healthier choices.

Three identified as having mental health issues surrounding their diagnosis and around the news that Covid-19 deaths within BAME groups and people with diabetes is “always on the news.”

Two mentioned their older parents are feeling isolated. One mentioned an 18-year-old family member is finding it difficult to adjust to being type one diabetic. He would like support from his peers.

Two out of three who mentioned they were struggling with mental health are single mothers.

Two participants discussed the difficulties in gaining help from services due to working hours not being within standard office hours.

Two participants mentioned that they are not worried about controlling their diet because “medication is controlling the sugar levels”. They are, however, concerned lack of exercise throughout the pandemic is not helping to keep weight down. They do not know where to find information about how to exercise in different ways.

One participant had had a breakdown in clinical service where although diagnosed as diabetic, at the time the GP had not informed the patient. She had to suffer various symptoms for a year before she was able to get care for her diabetes.

One has had a breakdown in the supply of dietician support due to the ending of one contract of a commissioned service and the new service has not contacted the patient. This is very frustrating for the patient as he has been waiting for three-months to continue his care.

Comparisons with local health and care experience profile

The insight from the engagement has provided an understanding of the differences people have from a range of backgrounds, health needs, and experiences they want from health and care services.

From the Profile we have written together with Healthwatch England, our feedback shows that people from a South Asian background are receiving the NICE recommended 9 key care processes within their GP surgery in a timely way. However, it also highlights patients would like further support or information at this appointment. The South Asian population we spoke to were not aware of integrated services that could assist with onward self-care.

It is recognized that South Asian communities with diabetes have a higher risk of developing secondary complications of cardiovascular and end-stage renal disease. Preventing further decline in health from the outset through providing information



about which integrated services are available would give a positive outcome for both patient and health services.

“the BAME community needs more frequent attention by services for diabetes. Considering the increased risk of other health issues, more regular contact may prevent other costly issues for both patient and the NHS”. (M 65-74.)

“I am a single parent and concerned about the costs involved with exercise and eating healthily. I would welcome any help through other integrated services”. (F 35-44)

“The stop smoking service would be helpful as I am trying to give up”. (M25-34)

From our group, only one had recently accessed secondary care. By chance, a problem with a toe was referred to a specialist. Previous visits to the GP had not enquired about foot health. This could have resulted in an amputation because of missed opportunities through health services. Other people may require services from a podiatrist, especially for high risk ethnicities. This example shows that if a person with a long-term condition is unaware of services, prompt self-care to manage their condition will be lost.

“I have had problems with my feet for years but had not been offered any podiatry care” (M 65-74)

Other feedback told us that people were more concerned about lack of exercise as they were able to control blood sugar levels through medication. This is an area of education that is lacking.

“The South Asian community generally do not worry about their diet but think that taking exercise will keep them healthy” (F 45-54)

Although our research has showed there are educational courses available and in different languages, they are not always offered, or available at a time that is suitable. It was highlighted that if courses were offered at diagnosis, the person may not have understood the value of these at the time as they were still dealing with the issues of having a long-term condition.

In March-April 2020 the South Alliance texted newly diagnosed prediabetic patients in the Ely area a link to the NHS Diabetes Prevention Programme. The uptake increased from an average 5 per one month to above 60 in one surgery. Giving a patient the option to attend an educational course at a later time (other than at the point of diagnosis) could improve uptake.



“working South Asians are not often able to attend educational courses due to their work patterns and hours”. (F 35-44)

It has been highlighted that people attending courses may not be the person carrying out the cooking and shopping. Opening the course for others in the family unit would mean dietary changes are more likely to be made.

“It would have been useful if my wife could have attended the course as she is solely responsible for the shopping and cooking” (M 45-54)

Some of the group were concerned about mental health support.

- The increased press coverage regarding higher deaths in the South Asian population who have diabetes.
- Those who feel isolated. Two single parents and some of our group who have older parents told us of their concerns that their mental health was in decline during the pandemic.
- Further information should be made available in different languages about local mental health support.

“I am struggling staying healthy, I am stressed and cannot sleep.” (F 35-44)

“I feel alone and isolated”. (M 45-54)

A highlighted gap in provision is the lack of community-based peer support groups. Although Diabetes UK have two digital groups in the Cambridgeshire area, more organized drop-in meetings targeting different age groups and languages at local community centers (when face to face meetings are allowed) would be an advantage. The South Asian population would be able to establish a relationship with a diabetes specialist nurse and access information about other integrated services, including mental health services. Providing support in a non-clinical setting could assist the person to manage their long-term condition better.

The group we spoke to were from second and third generation migrants. They would welcome a local digital platform for logging self-taken health tests and finding further information about diet, recipes, and local integrated services. Accessing information in Easy Read and via video format would be better for the South Asian group.

They did not think that their elderly parents who also had diabetes would find this useful.

“younger South Asians have the willingness to learn new things”. (M 65-74)



The feedback we received from the group has identified the same referral issues as local health systems. The CCG have listened to people with diabetes and are making plans to improve clinical and integrated care referrals. Although the pathways are incomplete and in draft format, it has planned a holistic care package. Staff will need to have training on the value of promoting this information as well as given extra time for patient appointments, especially to those from a background with existing socio-economic inequalities.

Recommendations.

- Improve information and support given at diagnosis. The right information given at the right time will support newly diagnosed people with long term conditions have better outcomes. However, offering information and support services throughout the long-term condition is equally important as the persons requirements change.
- Review the impact on the mental health of newly diagnosed diabetic people, especially from the South Asian ethnicity. Provide information to support mental health through integrated services on diagnosis and review at annual checks. (Using information in different languages, easy read versions and links to videos).
- Promote education courses at diagnosis and in relevant languages. However, it should be remembered that knowledge alone does not necessarily translate into action and it might be necessary to include other family and community members in behavioral change programmes.
- Prioritise setting up community peer support groups. South Asian communities have strong family networks, but these may not be able to support diabetes care. Online groups and when possible, face to face groups within community hubs will holistically support physical, emotional, social, and spiritual wellbeing. Promoting existing peer support groups via Primary Care would be valuable.
- Review the availability of appointments and care throughout the day and week to support those who have different working patterns.
- Ensure commissioned services are joined up when changing providers to prevent people being missed off the system and therefore losing their care.
- Develop the annual or drug review to highlight the importance of following a healthy diet and take exercise rather than rely on medication to control



blood sugars. This will help prevent further long-term health conditions such as heart disease. (N.B. Further support can be found at South Asian Health Foundation (SAHF) a registered charity founded in 1999 to promote good health in the UK's South Asian communities¹).

- The local STP have written a draft aspirational diabetes care pathway which includes peer support groups, apps, and Social Prescribers. It would be recommended to finalise and approve this as a priority as the South Asian diabetic community are not able to engage with services to support long-term conditions if they are not aware these are available.
- Review workforce training in Primary Care. Ensure the provision of information of other services is available to help manage the long term condition at the annual Nine-point diabetes check. This would improve day to day health and wellbeing for people with diabetes. The STP are developing a clinical work tool for SystmOne that will enable Primary Care teams to view all diabetes services at one point. This will assist staff awareness about integrated services.
- The STP are developing an app to enable patients to manage their own health digitally. This has been identified within this small sample of the 20-55 age group as being a useful tool if it also provides updated dietary advice and support in an accessible way. When this has been finalised, we recommend that it is advertised throughout the system to enable awareness.

¹ <https://www.sahf.org.uk/>

