Health and care experience profile briefing

Summary of work done to understand the needs of people from the South Asian community with diabetes

About the project

As part of a Healthwatch England project, our Healthwatch undertook some engagement work to understand the needs of local people of a South Asian origin living with diabetes. As part of this we developed eight health profiles detailing the experiences and needs of people within this population group.

The overall objective of the national project is for Healthwatch England 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, particularly for those undergoing transitions, or who are from a community that is more likely to experience health inequalities.

The qualitative approach will enable systems to ask what is and isn't working and provide an opportunity to explore why.

This piece of work is part of the early stages of developing this approach.

What we did

Healthwatch England and our Healthwatch undertook a review of what diabetes care should look like for people from a South Asian community.

And we recruited eight people from the South Asian Community to find out about their experience of diabetes care and explore any unmet support needs. This included through Thistlemore Medical Centre in Peterborough and from a local Diabetes UK peer support group for South Asians.

One-to-one interviews were held with each participant by phone and Zoom. Seven had used local primary care services only and one had recently used secondary care.

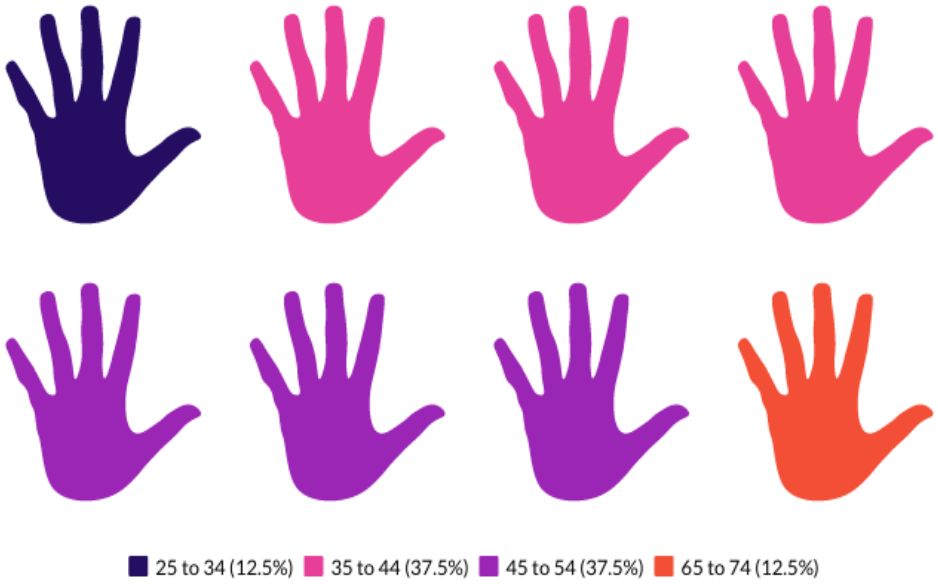
We chose this methodology rather than focus groups, as people told us that many members of their community would not be comfortable sharing their stories in a group environment, particularly if it was a mixed-sex group. It also allowed us to accommodate the individual needs of people.

A £25.00 "Love2 shop voucher" was offered for participants in the way of a thank you for attending the interviews.

Who we spoke to

We spoke to seven people from Peterborough and one from East Cambridgeshire. This included one person who was pre-diabetic, six who were type two and one who was type one. Five of our participants were male and three female. We had people from a mix of age ranges, between 25 and 75.

How old the people we spoke to are



What Healthwatch did

> "Each person with diabetes is constantly managing their condition. They need an NHS focused on supporting their self-management – by delivering care and support centered and coordinated around their needs."
> Diabetes UK

As part of the project, Healthwatch England mapped the national expectations of care for people with diabetes, including looking at the relevant NICE guidance and quality standards covering the management of type one diabetes[1], type two diabetes[2], diabetes in pregnancy[3] and prevention and management of diabetic foot problems.

They reviewed research from NICE, Diabetes UK and other organisations into improving care for people of South Asian heritage.

[1] NICE (2015) Type 1 diabetes in adults: diagnosis and management [NG17]

[2] NICE (2019) Type 2 diabetes in adults: management [NG28]

[3] NICE (2015) Diabetes in pregnancy: management from preconception to the postnatal period [NG3]

And the expectations for developing care for people with long-term conditions such as diabetes that are outlined in the NHS Long Term Plan[4].

What we looked at locally

Locally, we looked at how the Cambridgeshire and Peterborough Sustainability and Transformation Partnership (STP) draft Long Term Plan[5] set out the needs for people with diabetes, and we examined the local pathways and processes.

We also researched the local services that support people with diabetes. This includes the integrated lifestyle services, diabetic footcare, diabetic eyecare, and specialist acute care. As well as patient education services such as the national diabetes self-management education programme, DESMOND.

What people told us

The eight people we spoke to all confirmed that they are receiving the NICE recommended nine key care processes within their GP surgery in a timely way. But said they would like further support or information at and beyond this appointment. And they were not aware of the integrated services that could help them with onward self-care.

Better information

It is recognised that people from South Asian communities with diabetes have a higher risk of developing secondary complications of cardiovascular and end-stage renal disease.

> "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."
> Male diabetic patient, age 65-74

More targeted information about the integrated services available to support better diabetes care could help improve the health and wellbeing of this group.

> "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."
> Female diabetic patient, aged 35-44

> "The stop smoking service would be helpful as I am trying to give up."
> Male diabetic patient, aged 25-34

[4] NHS England (2019) NHS Long Term Plan

[5] Cambridgeshire and Peterborough STP (2019) Draft Cambridgeshire and Peterborough Long Term Plan, 29 November 2019

Only one of the people we spoke to had recently accessed secondary care when 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.

If a person with a long-term condition is unaware of services, opportunities for prompt self-care to manage their condition may be lost. This is especially important within high risk hard to reach ethnicities.

> *"I have had problems with my feet for years but had not been offered any podiatry care."*
> Male diabetic patient, aged 65-74

Lifestyle courses and management

Although our research found educational courses available in different languages, we found that they are not always offered at a time that suits potential participants.

> "Working South Asians are not often able to attend educational courses due to their work patterns and hours."
> Female diabetic patient, aged 35-44

One person suggested 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.

A project by the South Alliance (part of the local health and care system governance structure) where they shared a link for the NHS Diabetes Prevention Programme with newly diagnosed prediabetic patients in the Ely area, created a significant uptake in accessing the course. One surgery increased uptake from an average of five sign-ups per month to above 60 in one month. Thus showing that giving the option to attend an educational course at a later time (other than at the point of diagnosis) could improve uptake.

When they are on blood sugar medicines, people have said they are more inclined to eat as they want and not try to manage their diabetes through diet and exercise. And this tendency needs to be recognised by diabetes lifestyle support services.

Blood sugar and exercise - regular exercise is one way of helping to manage blood sugar levels. But some people were concerned about difficulty exercising during the pandemic making them more reliant on needing to control blood sugar levels through medication. They had a fear of not doing enough exercise to manage their blood sugar.

> "The South Asian community generally do not worry about their diet but think that taking exercise will keep them healthy."
> Female diabetic patient, aged 45-54

Benefits of other family members attending courses - we heard that the person attending courses may not be the one 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."
> Male diabetic patient, aged 45-54

Mental health support

Some were concerned about mental ill-health being exacerbated by the Covid restrictions and news about higher death rates from Covid in the South Asian population who have diabetes.

> "I am struggling staying healthy - I am stressed and cannot sleep."
> Female diabetic patient, aged 35-44

Two single parents and some of the participants who have older parents who also have diabetes told us their mental health was affected by isolation caused by the pandemic.

> "I feel alone and isolated."
> Male diabetic patient, aged 45-54

One person suggested that further information should be made available in different languages about local mental health support.

Our research found a lack of community-based peer support groups. Although Diabetes UK have two digital groups in the Cambridgeshire area, more organised drop-in meetings targeting different age groups and languages at local community centres (when face to face meetings are allowed) would be beneficial.

People could establish a relationship with a diabetes specialist nurse and access information about services in a non-clinical setting; this could help them manage their long-term condition better.

What would help people manage diabetes better?

The group we spoke to were from second and third generation migrants and told us they would welcome a local digital platform / an app for logging self-taken health tests and finding further information about diet, recipes, and local integrated services. But they did not think that their elderly parents who also had diabetes would find this useful.

They told us information in Easy Read and via video format would be better for some members of the South Asian group.

"Younger South Asians have the willingness to learn new things."
Male diabetic patient, aged 65-74

People told us that when they were first diagnosed, everything is very clinical and they don't always get the information they need about lifestyle services. There is not always time for the staff to give them advice about the services available to help them and also staff were not aware of what services are available.

We understand that the local STP / Integrated Care System (ICS) are developing a diabetes pathway to improve clinical and integrated care referrals.

Recommendations

- Improve information and support given at diagnosis and beyond. The right information given at the right time will support better outcomes for those with an existing diagnosis and the newly-diagnosed.
- Review the mental health impact of living with diabetes, especially for those of South Asian ethnicity. And provide information in a suitable format to support mental health at diagnosis and annual checks.
- Promote education courses at diagnosis and at other opportunities to increase take up. And consider including other family and community members in these 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.
- 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 nine-point check and other opportunities to highlight the importance of following a healthy diet and take exercise rather than rely on medication to control blood sugars.
- Implement the STP / ICS draft aspirational diabetes care pathway which includes peer support groups, apps, and social prescribers.
- Review workforce training in primary care so staff can signpost to relevant services at the annual nine-point diabetes check, or other opportunities.

We understand that the local STP /ICS is developing a diabetes pathway to improve clinical and integrated care referrals. We look forward to these recommendations featuring in those plans.