

# Integration Index Project

Health and Care Experience Profile #2  
A person of South Asian origin with diabetes

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## Introduction

Healthwatch Manchester was commissioned by Healthwatch England to feedback on the experiences of integrated care for those members of the local South Asian community who are living with diabetes.

## Methodology

Participant recruitment began in early 2021 and in the initial phase we used our established channels to source volunteers. Using these channels, we put out calls through our social media, Twitter and Facebook, and we also sent out e-bulletins to our members and supporters advertising the project.

Our next phase involved reaching out to the relevant external organisations and we asked them to distribute a project flyer to their members, volunteers and service users. This included organisations such as Diabetes UK and the National Institute for Health Research (NIHR).

We were also able to find participants through a number of our board members, who had links to individuals and local community groups whose remit fitted the necessary criteria.

With our recruitment complete, over the course of three weeks we conducted one-on-one interviews with 20 participants. 19 of the interviews were conducted over the telephone and 1 was conducted using Microsoft Teams.

A breakdown of our participants is as follow:

- Men (13) and women (7)
- Age breakdown: 25-35 (1), 35-44 (3), 45-54 (1), 55-64 (2), 65+(9), DK/Didn't want to give (4)
- Diabetes type - type 2 (17), type 1 (3)

## Results

### **Q.1 In order to treat your diabetes, which services do you require support from?**

#### Key findings

- The most used services were the GP and pharmacy, with all participants saying that they used these services
- A majority of participants (60%) said that they had been referred to the hospital for specific treatment such as regular eye check-ups and appointments with consultants, whilst one reported to have used the hospital when in need of emergency treatment
- A few (25%) reported receiving treatment from a health centre, with this figure also including those who have been treated at a specific diabetes centres, mainly used for eye tests
- Under half of our participants (35%) reported having used any sort of local community service such as a dietician or health & wellbeing services. This issue will be discussed in more depth later in the report.

#### Analysis

The common services used by all participants became clear after the first few interviews. All had reported visiting their GP on a regular basis (usually once a year) for a simple checkin, although the pandemic has obviously altered the frequency of visits. All participants used the pharmacy to receive their medication. However, after this a mix picture began to emerge with their being some variation in the services accessed. Many people (60%) reported having regular eye tests but after that there was little consistency. As reported above, under half the participants said that they had used any sort of local community service and it was clear that some had never even had these options discussed with them, whilst others were aware of the different available services.

## **Q.2 To what extent have you been involved in your care?**

### Key findings

- 50/50 split on involvement in care
- The numbers were split similarly on the issue of family involvement in care
- Lack of support for family members for whom English is not their first language

### Analysis

As above, the reporting on the involvement in their own care was evenly split between the two camps. I spoke to some people who were clearly very active in researching the available treatments and made suggestions about the treatment which they would like, whilst other people were clearly very happy to agree to the treatment plan outlined by their healthcare professional.

Out of those who liked to play an active role in their care, the vast majority reported that their suggestions were well received by the healthcare professional. However, one participant expressed concern that on the occasions when he had made suggestions, he didn't feel that it lead to any change in his treatment and was effectively fobbed off with a list of reasons why it wasn't possible.

There was quite a variety in the extent to which family were involved in their treatment. Some reported that their family was quite heavily involved in their treatment, attending all the appointments with them and taking an active role in their treatment, whilst others clearly preferred to deal with their health issues themselves and didn't want to involve family too much in the process.

One participant reported being diagnosed with the condition at a young age and having her family accompany her to the appointments. At the time her Mum did not speak English well and so did not understand what was being discussed during the meetings, and the participant felt that more could have been done to have made her Mum feel welcome and more included in what was going on.

## **Q.3 How well do the different health and social care professionals involved in your care work together? Do you think your health and care services are joined up successfully?**

### Key findings

- Generally, the participants reported being quite satisfied with the way the different services worked together
- There were two main issues which were highlighted - information sharing and concerns of a fragmented system

### Analysis

As stated, the majority of respondents reported being satisfied with the way their healthcare services worked together. For those who did express a concern, the main issues were around information sharing and the way in which the different departments 'kept themselves to themselves'.

On the first point, one participant reported on a situation in which information was not shared between the two hospitals he had visited for treatment. He said that information relating to his condition had not been made available from one to the other which became clear when he was discussing his treatment at one hospital to the other. Whilst this did not appear to have a major impact on the treatment of this particular participant, this is certainly an area of concern due to the possible consequences. In total, 20% of our participants reported having concerns about information sharing.

With regards to the issue of a fragmented system, a couple of respondents felt that departments/specialities focussed solely on their area of expertise, which was not a problem in itself, but they expressed a feeling that nobody was looking at the overall picture of their health and that a more holistic approach was required. One participant felt that there needed to be all the services under one roof, rather than having to go to a number of different sites for treatment of one condition.

However, it should be noted that overall people were satisfied with the way each service worked together.

### **Q.4 How has GP or community services supported the participant? Used local services not hospital or day-to-day?**

#### Key findings

- Despite mainly positive reporting, we did receive some concern about GPs
- We received some reports of GPs not fully understanding the condition
- Concern about GPs moving online, getting appointments can sometimes be problematic
- Not many participants had used diet/exercise/therapy services or had any knowledge of them at all
- Those who had used them reported that they had to be the one to make the suggestions and had to do the legwork themselves
- Little information seems to be shared about the services which are available
- Little focus on culturally appropriate services
- Inadequate signposting

### Analysis

In general, the reports about the service experienced with a GP was very positive. However, a couple of participants felt that their GP did not fully understand the condition and one reported that she had to explain type 2 diabetes to her GP.

One of the majorly negative topics recorded in the interviews surrounded the accessibility and of community services, such as health & wellbeing dietary and exercise services. Under half of our respondents reported as having used any such service since their diagnosis with diabetes (40%), whilst a number of those people had reported not having used such services for 10+ years. Many participants reported that they would like to access such services but were unaware of the services that were available. For those people who had been able to access such local services, they had only found out about them by doing the leg work themselves and specifically asking their healthcare professionals about them, rather than the relevant services being made known to them by healthcare professionals.

Exactly half of our respondents, including some who had already these services, told us that they would like access one or more of these services in the future. One of the most requested services was dietician, although some did raise concerns about their experiences of accessing this service. A number of participants who had used dietary services felt that they were too focussed on traditional English diets and they were unable to alter their programme to cater for people from the South Asian community with different dietary requirements. They clearly felt that there was a lack of awareness about their dietary requirements and this put them off from continuing to access the service in future.

## **Q.5 Explore experiences of screening process, support and referrals**

### Key findings

- Most participants reported to having been referred for a specific service
- Overwhelming response was positive - few problems reported
- One participant did report concern about receiving results

### Analysis

A number of participants reported having received treatment for other medical conditions unrelated to their diabetes but there was little interaction to note. One participant reported having a heart condition which raised concern about the impact on their diabetes treatment, but this was resolved quickly with their GP and the participant was very happy with how it was handled.

## **Q.6 Interactions between diabetes treatment and treatment for other medical conditions**

### Key findings

- No issues reported

### Analysis

A number of participants reported having received treatment for other medical conditions unrelated to their diabetes but there was little interaction to note. One participant reported

having a heart condition which raised concern about the impact on their diabetes treatment, but this was resolved quickly with their GP and the participant was very happy with how it was handled.

#### **Q.7 Have they used rehabilitation services?**

No participants reported using rehabilitation services

#### **Q.8 Other issues**

- The young person I spoke with raised a point about the impact on mental health after being diagnosed with the condition. She is in contact with a group of young people of a similar age who have diabetes and she feels as though there is not enough support for those people to deal with the diagnosis, and believes that this is a mental barrier for these people being effectively treated
- Quite a number of participants felt that there should be specific services designed for diabetic patients. They felt that the condition is not taken as seriously as it should be