healthwatch
Manchester

Working in Isolation?

A report looking into the experiences of integrated care for two Manchester communities

August 2021

Contents

Executive summary

1. Healthwatch Manchester was commissioned by Healthwatch England to review the integrated care arrangements for two specific groups of people: (a) people from the South Asian community who have diabetes (persona 2), and (b) black men with multiple health conditions, including recent experience of cancer care (persona 4).

2. This commission formed part of a larger national investigation overseen by NHS England, the aim of which was to investigate more fully the findings from the NHS Long Term Plan consultation in 2018. The 2018 consultation was implemented by Healthwatch England through the national Healthwatch network of local Healthwatch organisations and their workforce.

3. This report draws upon the findings and recommendations from the two Greater Manchester studies and was conducted by Healthwatch Manchester. The audience for this report includes the new Integrated Care Service for Greater Manchester: Greater Manchester Health & Care Partnership and its associated strategic bodies.

4. Two studies were conducted, one by Healthwatch Manchester exploring integrated care for persona 2, the other by the Caribbean & African Health Network (CAHN), exploring integrated care for persona 4.

5. Following the conclusion of the studies and the analysis of the responses, three key findings were identified.

   Firstly, respondents from both studies expressed concerns regarding the fragmented situation of health and care services, with particular emphasis on the information sharing between healthcare providers.

   Secondly, integrated care was not met for either persona with respect to ethno-cultural requirements or expectations.

   Thirdly, the levels of referrals into and the quality of information regarding social prescribing services were reported as very low for both personas.

6. Whilst our respondents were satisfied overall with the level of care that they had received or are receiving, it is clear that integrated care requires significant improvement in order to fully meet the needs of people within these two personas.

Recommendations

1. Action needs to be taken to improve the coordination of information exchange between services. A review of information management between the service providers mentioned in this report would highlight the areas requiring improvement.

2. Services need to ensure that, where possible, they are culturally sensitive. Information needs to be provided to the patient in culturally appropriate and accessible ways.

3. A review of social prescribing services should take place in order to establish the local offer in each of the ten localities of Greater Manchester for each persona. Once established, referral into these services needs to be incorporated into care pathways for each persona.

4. The methodology employed in this study and its inclusion in the national methodology should be considered when conducting future work of this kind in Greater Manchester.

Working in Isolation

Persona #4

Black men with multiple health conditions, including recent experiences of cancer services

Foreword by Charles Kwaku-Odoi, Healthwatch Manchester Board Member

Black men in the United Kingdom face some of the most significant challenges when striving for good health and ways to improve their health outcomes. There are many factors that influence whether Black men achieve optimal health and wellbeing, which requires an examination through an intersectional lens in which to examine the obstacles faced by this demographic. In 2007, Dr Kwame McKenzie articulated this succinctly when he wrote in the Guardian how 'Being Black in Britain is bad for your mental health'. We can clearly evidence how the impact of unfair treatment across education, limited access to good employment, harsher treatment in the criminal justice system, and poor access to health and adequate housing can result in higher rates of mortality and morbidity. There is a lack of trust and a reluctance to connect to a health system that Black men view as treating them unfairly, as seen in our mental health institutions. The health of Black men is a serious public health problem and the inequalities experienced require a joined-up approach across sectors to fix them.

The Caribbean and African Health Network is working to eradicate these health inequalities within a generation for Black people. We welcome the emphasis placed in the long-term plan on new ways of working to address the increasing numbers of people living with multiple co-morbidities. As an organisation we recognise the importance of working in an intersectoral way to join services together to prevent additional pressures on the NHS and to indeed address the needs of those affected.

We were delighted to be working with our Healthwatch partners who had an agenda to explore how Black men living with cancer and other co-morbidities experienced health care across services. The results from this small-scale study were incredibly enlightening because overall, Black men's experiences were significantly dependent upon the relationship they had with their primary care provider. One of the findings was that Black men who had a GP from their own cultural background had a more positive experience of care. Black men spoke about how they were supported in a culturally appropriate way and referred to appropriate services in a timely and coordinated way.

We would like to thank Healthwatch for approaching us to work with them to expose any challenges for Black men and to provide a picture of 'what good looks like' in the Black man's journey to better health.

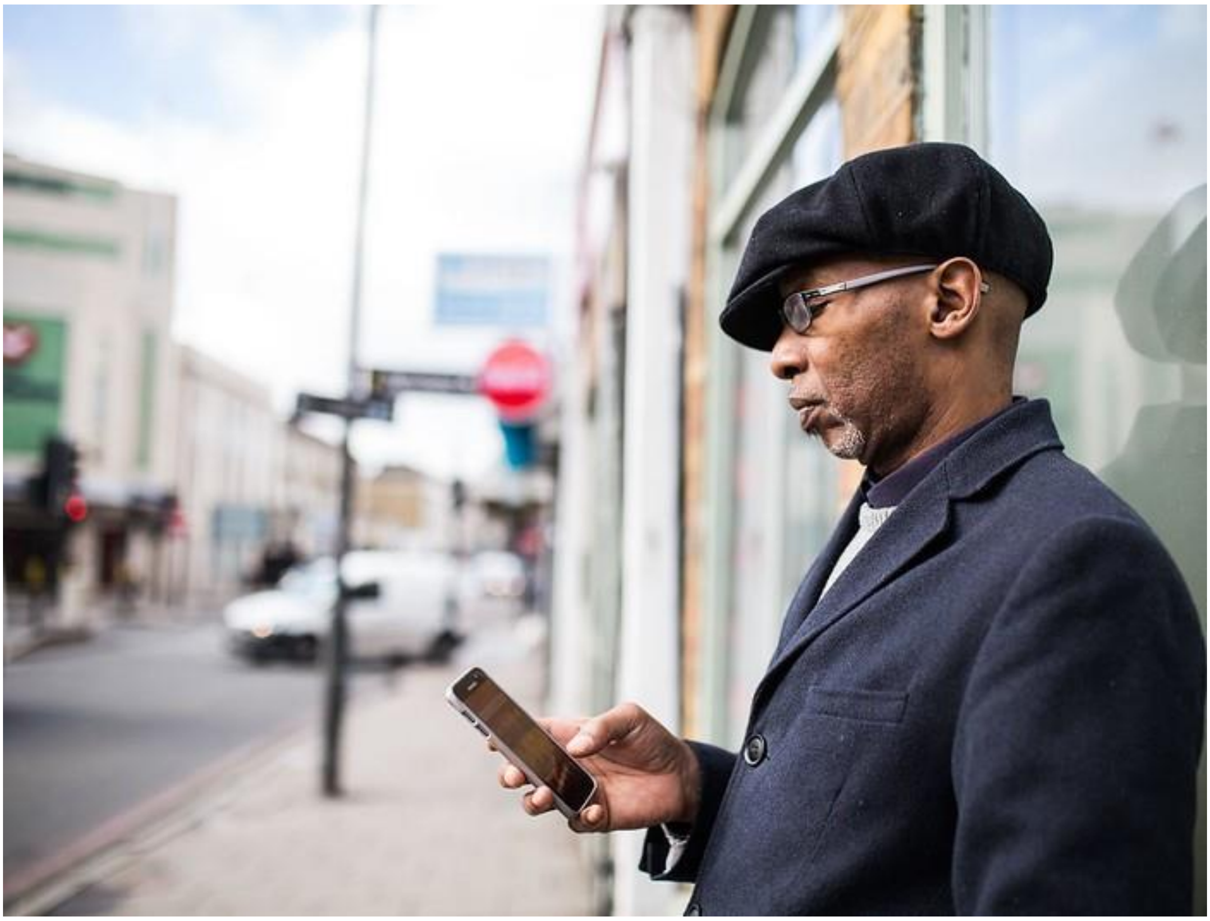
1. Introduction

1.1 Healthwatch Manchester was commissioned by Healthwatch England to feed back on the experiences of integrated care for local black men who are living with multiple health conditions, including recent experience of cancer services.

2. Methodology

2.1 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 presence, primarily Twitter and Facebook, and we also sent out e-bulletins to our members and supporters to advertise the project.

2.2 Our main source of recruitment was through one of our board members, Charles Kwaku-Odoi, who is the chief officer of CAHN (Caribbean & African Health Network). CAHN is a CIC (community interest company) that works with the local Caribbean and African communities to reduce health inequalities.



2.3 With recruitment complete, interviews were arranged with all participants. The interviews were conducted by someone who was familiar with qualitative interviewing in an ethical manner and all ethical practices were adhered to, given the nature of the enquiry.

2.4 All men consented to their interviews being recorded and for us to cite them anonymously in this report. General Data Protection Regulations (GDPR) were adhered to throughout the process.

A breakdown of our participants is as follows:

- Men (6)
- Age breakdown: 55-64 (3), 65+ (3)
- Type of cancer: Prostate (5), Colon (1)

3. Results

3.1 Firstly, we asked our participants to list the services that they require support from in order to treat their condition(s).

Key findings

- GPs and hospitals were used by all of our participants
- All expressed a positive relationship with their current GP
- Big difference having a GP from the same community
- Varied experiences with hospital and other services
- More focus required on mental health and wellbeing services

3.2 We asked those who listed their GP as a service they required support from to expand on their experiences.

All men spoke about the positive relationship they had with their GP, from the point of their initial consultation right through to their subsequent treatment. Interestingly, 5 out of the 6 men all had a black GP. One participant stated that:

"My GP was brilliant and because he was Nigerian, they really understood why I was so anxious."

All men shared challenges with getting to the final diagnosis when referred to a consultant. One participant shared his experience:

"I have a great relationship with my GP. I went to see my GP as [sic] something was not quite right, and she examined me. And she says, she can't find anything wrong with me. So, she then decided to make an appointment for me to go and have, you know, the colonoscopy. It took a year to get the appointment, which kept on getting cancelled."

Whilst all reported a positive relationship with their GP, one of our participants did share a negative experience he encountered. He said he felt let down by his GP when he raised concerns about his health, that he didn't feel listened to and taken seriously and was sent away twice when his GP refused to refer him to a specialist for another opinion:

"I went twice to my GP and they did nothing, they just told me to keep monitoring the inability to pass urine, I don't know what they were thinking. I eventually brought a church friend with me who happens to be a nurse and then he decided to refer me and I then got my diagnosis soon after; I wasn't happy with the delay."

A different participant had a number of health concerns along with his cancer diagnosis, but he didn't feel well looked-after by the practice, and decided to change:

"I wasn't happy with where I was, I did not even know I had a serious problem with my kidney until I moved practices, I am so glad I have a black GP now because he took me seriously when I had problems and needed an examination for prostate cancer."

3.3 We asked those who listed a hospital as a service they required support from to expand on their experiences.

One participant spoke about his referral to his secondary care services and how they responded quickly when they received the referral from his GP. However, he was annoyed that it took so long to get an initial colonoscopy:

"As soon as they got the referral from my GP the second time around with the diagnosis from Germany, I was asked to come in within 2 days for another colonoscopy, which confirmed colon cancer. I was offered surgery and was involved in the planning of this care. The consultant was marvellous. The surgery, though, took 4 hours, when it would normally take about an hour, because they found that some other surgery for a hernia I had in Jamaica wasn't done right and they fixed that."

The same participant then spoke about his chemotherapy treatment and how well they kept him informed about his condition:

"On the whole, they tell me everything, when my blood is good and when it's not. I cannot complain. Because, you know, I have a good relationship with my consultant and with a clinical nurse. And all the nurses, even men are going to get my blood and they all have a good laugh and a joke, you know?"

He also went on to identify a few delays he had encountered when he went to his appointments:

"Sometimes things take long because nearly every time I go in they are short-staffed and when there is an emergency, I am waiting a long time, but it is a hospital, things happen."

A different participant told of his experience when he had made up his mind up to have surgery. He said that there were no beds at the local hospital, so his consultant arranged for him to go elsewhere so the surgery wasn't delayed:

"He asked me if I was happy to go to the private hospital and have my surgery there, he told me that he would still look after me… I was so grateful because by this time I trusted him, he was like my family, a good man from somewhere, I think Nigeria."

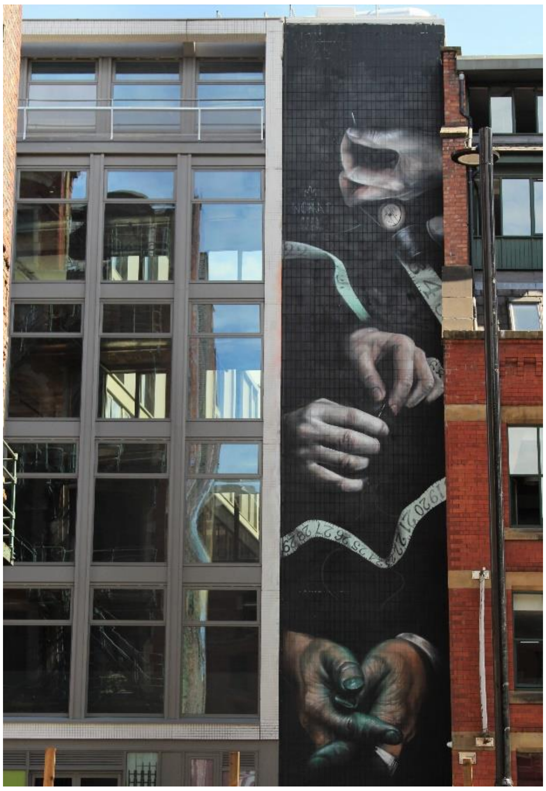
A further participant spoke about how well informed he had been about his PSA (Prostate-Specific Antigen) levels, which started to rise again even though he had had surgery to remove his prostate:

"The hospital informed me that my PSA levels had risen again and although they could not see anything, they suggested they do radiation therapy, which I agreed to."

One participant talked about his disappointment with the lack of focus on mental health and personal wellbeing:

"When I go to the hospital or the doctor, they only talk about the prostate issues but never ask about how I am feeling…"

Another participant spoke about his experience of counselling services:



"I was offered the talks about counselling you know… they talked a lot about mental wellbeing support, actually my work is sort of in and around mental illness. So I'm kind of I'm aware enough to be really well with mental health. And as I said… I've got a very supportive family network around me. Every appointment they would ask me how I'm feeling, you know, whether I need to access any other kind of service. We got through it really, you know, with the support that we got at the beginning, you know, when you get a diagnosis, you work through it. Yeah, I've kind of come to terms with it. You know, I'm still here. So, 15 years later and still using services but all good."

3.4 Following our conversations about experiences at the GP and the hospitals, we then asked participants who had used other services to expand on their experiences.

During the course of the discussions, some participants did identify other services that they had accessed as part of their treatment. For example, one participant indicated that he had accessed information to support him with his diet but did not find it a useful experience. His feedback was that the information was not culturally appropriate and not relevant to him and his life. Another participant said that he had been referred to the Macmillan support group but *"felt out of place"*. He then found a group that was specifically for black men, and he found this a much better experience.

3.5 We then asked participants to what extent they have been involved in their care.

Key findings

- All participants felt involved in their care
- Some had family who were involved in their care

One of the men had an advocate with him and knew senior clinicians from the service he was using:

"When I had my first referral to a consultant team, I was not happy about the way they treated me, they basically told me that I had no option but to have my prostate removed. It always helps when people know you; as soon as I told the consultant who I knew at the cancer hospital and the person with me introduced themselves I found I was being treated very differently and given different options to discuss."

A further participant talked about how he was made to feel involved in his care:

"I felt very involved and I was given options about chemo, radiotherapy or surgery. So I said to him which way you think is the best way? He said to me, it's up to me."

One also spoke about how he felt involved in his care all the way through, stating that the consultant involved his wife as well and did not make any assumptions about what they wanted:

"I found the hospital services very good and well-informed about what to expect from the different options. Because of my mental health issues, I was concerned about managing my mental health and also the medication for my high blood pressure, I was concerned about how the therapy would interact and it was my GP that really helped with that."

3.6 We then asked participants how well they felt the different health and social care professionals involved in their care worked together, and if they felt that their health and care services were joined up successfully.

Key findings

- Generally, the participants reported being quite satisfied with the way the different services worked together
- Feeling that each service solely focused on their speciality but there was little oversight
- Some concerns were raised about communication between services

Whilst the overall was positive, one participant did not feel the services worked well together, leaving him with a sense that the service was only focused on their particular area:

"…it is like a checklist of questions they go through, nothing is joined-up, even in the GP practice, it is a quick check, after that you are left on your own."

Furthermore, some of the participants shared their frustrations about joined-up services and how hospitals and systems did not speak to each other when they had to address more than one health condition.

3.7 Following on from the previous question, we then asked participants to share their experiences of the screening process and then support and referrals for treatment.

Key findings

- Overwhelming response was positive
- Although some problems identified around appointment delays

In the main the response was very positive, although a couple of participants did reference delays to their appointments occurring after they had been referred by their GP. One participant stated:

"Sometimes things take long because nearly every time I go in they are short-staffed and when there is an emergency, I am waiting a long time, but it is a hospital, things happen."

3.8 We then asked participants to share their experiences of interactions between cancer treatment and treatment for any other health condition.

No participants reported any issues with the interaction between their treatment for cancer and treatment for other medical conditions.

3.9 We then asked if our participants had used rehabilitation services.

No participants reported using rehabilitation services.

3.10 We then opened the floor and asked if there were any other relevant issues they would like to raise with us.

All men had family and friends to rely on for emotional wellbeing support, and although one of the men highlighted stigma around the cancer diagnosis, they all highlighted the importance of family, friends, church members and advocacy support to help them to navigate the system and get the support they needed to deal with their conditions.

Men discussed the information they had received when they were diagnosed, including information signposting them to relevant activities. Overall, men found the information leaflets to be very unhelpful. They stated that nothing pointed to cultural or religious factors that will influence care and how they engage with services.

“To be honest, the information leaflets were very unhelpful, I skimmed through them and put them in the bin.”

“The leaflets are a waste of time, they had nothing on them to help me with my diet.”

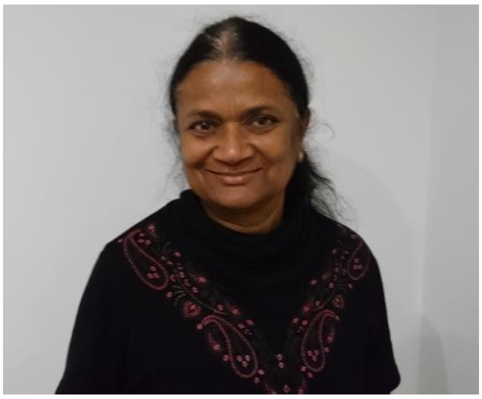
Recommendations

1. Where possible, acknowledge and match cultural sensitivity regarding practitioner and patient, especially at diagnosis of cancer.
2. Ensure information and follow-up support is tailored to the needs of this persona.

Working in Isloation

Persona #2
A person of South Asian origin with diabetes

Foreword by Dr Mina Desai CBE, Healthwatch Manchester Board Member



In April 2021, NHS England and NHS Improvement embarked on a long-term project to provide an integrated care system (ICS) to all parts of England. Key to this project is a well-grounded and robust understanding of people's views on the priorities and delivery of their local care systems.

Owing to its expertise and track record, Healthwatch England was asked by NHS England to engage people across the country about how people wanted the priorities to be implemented locally.

Between March and June 2019, the Healthwatch network carried out 500 focus groups, attended 1,000 events and engaged tens of thousands of people online to find out what people want from the next ten years of the NHS. This rigorous and insightful report is one of the products of that research.

This study, carried out by Healthwatch Manchester and the Caribbean & African Health Network (CAHN), provides fine-grained insight into views on the integrated care arrangements for two key groups of people: (a) people from the South Asian community who have diabetes, and (b) black men with multiple health conditions, including recent experience of cancer care.

Focusing on the first group, type 2 diabetes is up to six times more common in people of South Asian descent than in the broader UK population. The consequences of this fact on healthcare systems are evident: for example, it partially explains why the UK's South Asian population is 19% more likely to die of complications from coronavirus.

This report is thus timely and essential. It tackles matters of core concern for local integrated care provision in Manchester. It does so on the basis of a wealth of data generated from a close and careful engagement with grassroots communities, and with a methodological approach that is accessible and well-tailored to understanding their views and needs.

The recommendations put forward in this report are thus robust and actionable: they are ready to be incorporated into the referral and care pathways for people with diabetes in Greater Manchester. In so doing, they could lay the foundations for a culturally appropriate and locally-rooted coordination of services and information in a way that will enhance the effectiveness of integrated care provision and satisfy the needs of patients.

1. Introduction

1.1 Healthwatch Manchester was commissioned by Healthwatch England to feed back on the experiences of integrated care for those members of the local South Asian community who have diabetes.

2. Methodology

2.1 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 Twitter and Facebook, and we also sent out e-bulletins to our members and supporters to advertise the project.

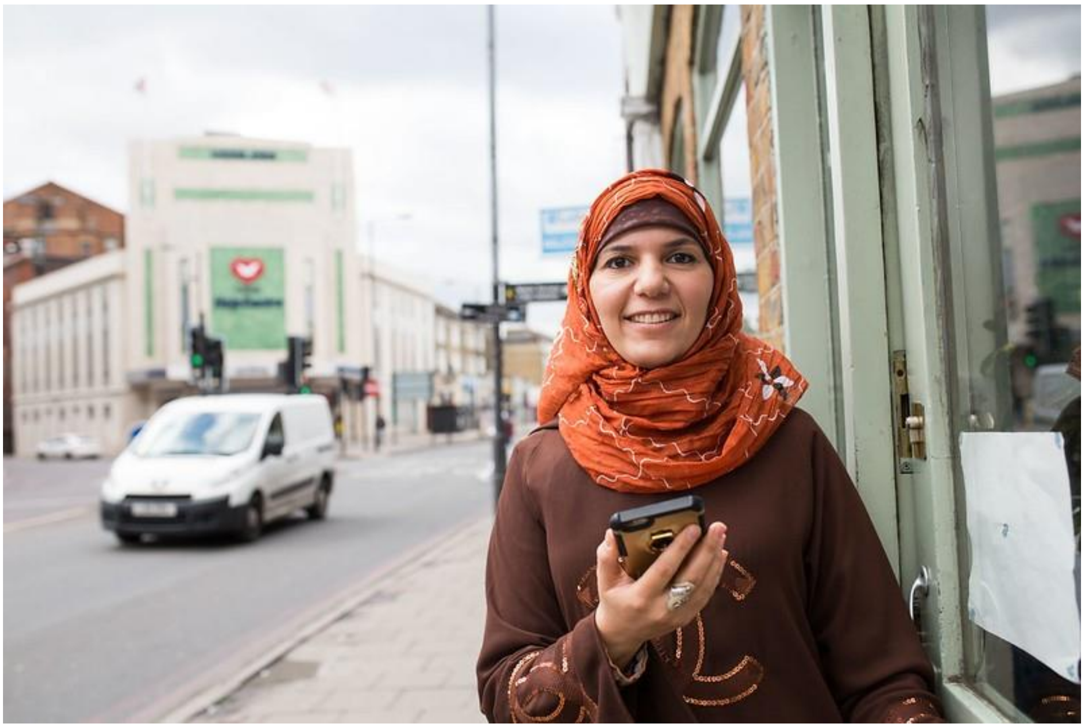
2.2 The next phase involved reaching out to the relevant external organisations and asking them to distribute a project flyer to their members, volunteers and service users. This included organisations such as Diabetes UK and the National Institute for Health Research (NIHR).

2.3 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.

2.4 With our recruitment complete, over the course of three weeks we conducted one-on-one interviews with twenty participants. Nineteen of the interviews were conducted over the telephone and one was conducted through an online video call.

A breakdown of our participants is as follows:

- 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)



3. Results

3.1 Firstly, we asked participants which services they used in order to treat their diabetes.

Key findings

- The most used services were the GP and pharmacy, with all participants saying that they used these services
- 60% reported that they had been referred to the hospital for specific treatment such as regular eye check-ups and appointments with consultants, whilst one reported having used the hospital when in need of emergency treatment
- 25% reported receiving treatment from a health centre, with this figure also including those who have been treated at a specific diabetes centres. This service was mainly accessed for eye tests
- 35% reported having used any sort of local community service such as a dietician or health and wellbeing services

It became clear which services were commonly used by participants after the first few interviews. All had reported visiting their GP on a regular basis (usually once a year) for a simple check-up, although the pandemic has obviously altered the frequency of visits. All participants used the pharmacy to receive their medication. However, after this a mixed picture began to emerge, with some variation in the services accessed. 60% reported having regular eye tests, but this was one of a small number of services that had been accessed by a large portion of our participants. 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.

3.2 We then asked participants the extent to which they had been involved in their 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

A number of participants were clearly very active in researching the available treatments and made suggestions about the treatment they would like, whilst others 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 did not feel that it led to any change in his treatment and felt that he was effectively '*fobbed off*' with a list of reasons for which it was not possible.

There was quite a variety in the extent to which family was involved in 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 did not want to involve family in the process too much.

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 make her Mum feel welcome and more included.

3.3 We then asked participants how well they felt the different healthcare professionals involved in their care worked together, and if they felt that their health and care services were 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 that were highlighted – information sharing and concerns about a fragmented system

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 by one to the other, which became clear when he was discussing his treatment at both facilities. In total, 20% of our participants reported having concerns about information sharing.

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

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

3.4 We then asked participants how their GP or local community services supported them.

Key findings

- Despite mainly positive reporting, we did receive some concern about GPs
- Little information seems to be shared about the services that are available
- Little focus on culturally appropriate services
- Inadequate signposting

In general, the reports about the service provided by a GP were 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 most frequently raised concerns was around the accessibility of community services, such as dietary and exercise services. Under half of our respondents reported having used any such service since their diagnosis with diabetes (40%), whilst a number of those people stated that they had not used such services for 10+ years. Many participants reported that they would like to access such services but were unaware of the local services that were available. For those people who had been able to access such services, they had only found out about them by conducting research themselves and raising this with their healthcare professionals, rather than the other way around.

Exactly half of our respondents, including some who had already used these services, told us that they would like to access one or more of these services in the future. One of the most requested services was that of a dietician, although some did raise concerns about their previous experiences of accessing this service. A number of participants who had used dietary services felt that they were too focused on traditional English diets, and it was not possible to alter the programme to cater for people from the South Asian community with different dietary needs. They felt that there was a lack of awareness and interest, which resulted in them not continuing to access the service.

3.5 We then asked participants about their experiences of the screening process, support and referrals for treatment.

Key findings

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

The participants reported overwhelmingly positive experiences of the screening process, support and referrals for treatment. No major issues were reported.

3.6 We then asked participants about the interactions between their diabetes treatment and treatment for other medical conditions.

Key findings

- No issues reported

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.

3.7 We then asked participants if they had used rehabilitation services.

No participants reported using rehabilitation services.

3.8 We then opened the floor to our participants and asked if they would like to raise any other relevant issues with us.

One of our younger participants 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 there is not enough support for those people to deal with the diagnosis, and believes that this is a mental barrier to 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 was not taken as seriously as it should be.

Recommendations

1. Ensure health practitioners have relevant and current information regarding referrals into support services.

2. Refer patients to Diabetes My Way in order to ensure as many people living with diabetes as possible through the use of the resources available are supported to self-manage and avoid unnecessary admissions to hospital or the development of longer-term complications.

3. Ensure practitioners have an overview of each individual’s requirements.

Acknowledgements

Healthwatch Manchester would like to thank the following for their support with this project:

Charles Kwaku-Odoi
Caribbean & African Health Network
Mina Desai
Jain Samaj
Ewan Jones, Katherine Grady
Greater Manchester & Eastern Cheshire Strategic Clinical Networks - Diabetes
Ali Jones
Greater Manchester Cancer Team
Warren Heppolette
Greater Manchester Health & Social Care Partnership
Healthwatch England
The National Healthwatch Network
The Healthwatch Manchester Reading Panel

healthwatch
Manchester

Canada House
Chepstow Street
Manchester
M1 5FW

0161 228 1344

info@healthwatchmanchester.co.uk

www.healthwatchmanchester.co.uk

Company Limited by Guarantee registered in England No. 8465025