

# Integration Index Project

**Health and Care Experience Profile #4  
Black men with multiple health conditions,  
including recent experiences of cancer  
services**

## Contents

Introduction .....	3
Methodology.....	3
Results .....	3

## Introduction

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

## 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 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) which works with the local Caribbean & African communities to reduce health inequalities.

With recruitment complete, interviews were then conducted with all participants. All men provided consent to take part and all men were happy to have their voice recorded for notes and to cite them anonymously in the report. GDPR was adhered to throughout the process.

A breakdown of our participants is as follow:

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

## Results

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

#### **Key findings**

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

#### **GP**

All men spoke about the positive relationship they had with their GP, from the point of their initial consultation right through with their subsequent treatment. Interestingly, 5 out of the 6 men all had a black GP and this was noted by a number of participants. 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 consultant. One participant shared his experience, which included a long delay:

*“I have a great relationship with my GP. I went to see my GP 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 which he encountered. He said he felt let down by his GP when he went with 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 he was 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 a examination for prostate cancer”*

### Hospital

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 have a good relationship 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 things he regarded as expected delays 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 him when him and do the surgery, 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 levels which started to rise again even though he had surgery to remove his prostate:

*“The hospital informed me that my PSA levels had risen again and although they could see anything, they suggested they do radiation therapy which I agree too”*

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 their experience of counselling services:

*“I was offered the talks about counselling you know, when I got to Christie, they talked a lot about mental wellbeing support, actually my work is sort of in in around mental illness. So I'm kind of I'm aware enough to be really well with mental health. And as I said, about quite supportive I've got 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 service but dealt with Reducing Health Inequalities, Influencing Policy & Practice 7 everything else by myself and with my family. 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'm kind of come to terms with it. You know, I'm still here. So, 15 years later and still using services but all good”*

### Other services

During the course of the discussions some participants did identify other services which they had accessed as part of their treatment. For example, one participant indicated that he had accessed dietary requirements 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 which was specifically for black men and he found this a much better experience.

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

### Key findings

- All participants felt involved in their care
- Some had family who were involved in their care
- Few concerns raised about this aspect

## Analysis

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 what which way you think is the best way? is said to me, it's up to me. I think it was a T seven or something like that”*

One also spoke about how he felt involved in his care all the way though, stating that the consultant involved his wife as well and didn't 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”*

## **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
- Some concern over mental health referrals
- Sense that each service solely focussed on their speciality but there will little of overall oversight
- Identified issues about the communication between different services

## Analysis

Whilst overall the response to this question was positive, one participant did not feel as though the services worked well together, leaving him with a sense that the service was only focussed 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”*

A point made by one of our participants which is referred to earlier in this piece (regarding lack of focus on mental health), was in contrast to another of our participants who felt as if their mental health concerns had been taken seriously. Whilst this is obviously only a small sample size, it is interesting to note that there is clearly not a standard approach to this issue across the board. How is it that one patient was referred to relevant mental health services, whilst another patient had not had this service even mentioned to them? This would indicate a weak connection between the two services.

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.

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

#### Key findings

- Overwhelming response was positive - few problems reported
- Problems related to delays in appointments

#### Analysis

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

*“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”*

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

#### Key findings

- Reported under Q3

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

No participants reported using rehabilitation services

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

- 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 through their conditions
- Men discussed the information they had received when they were diagnosed and activities, they could be involved in which was provided in verbal formats and in the form of leaflets. 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. It is clear that a more culturally appropriate approach is needed in order to fully engage all communities.

*“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”*