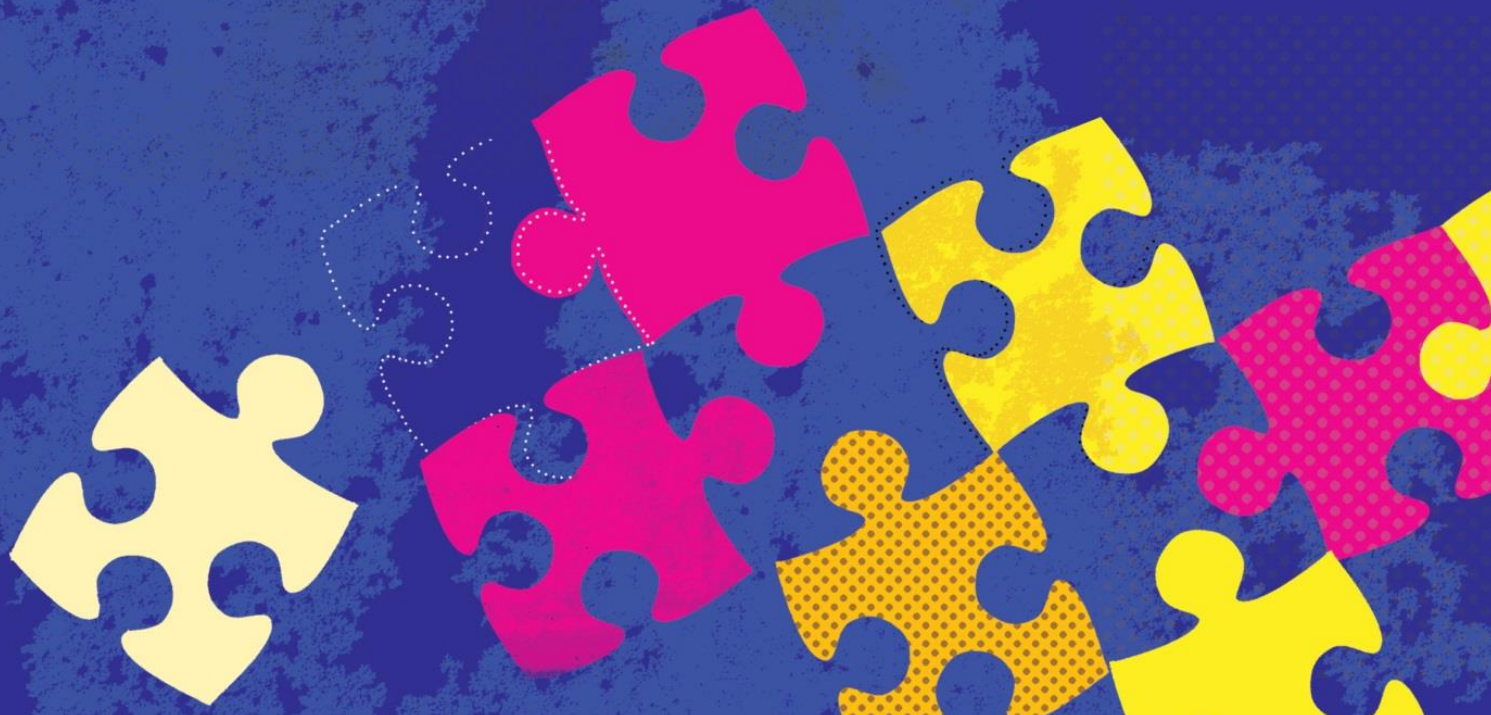


Making the most of primary and community services: what works for BAME people with long-term conditions?

December 2016



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RESEARCH REPORT

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December 2016

Acknowledgements

This research was undertaken by a team from the Centre for Regional Economic and Social Research (CRESR) and Centre for Health and Social Care Research (CHSCR) at Sheffield Hallam University, on behalf of NHS Nottingham Clinical Commissioning Group. The research would not have been possible without the commitment of 86 research participants from across the City of Nottingham or seven local voluntary and community organisations that facilitated their participation:

- Nottingham Chinese Welfare Association
- Asian Women's Project
- Afro-Caribbean Women's Group (men welcome), Queens Walk Centre
- Gambian Community Centre
- African Focus group (organised and delivered with Self Help UK and City CCG)
- The Signpost to Polish Success
- Indian Community Centre Association
- Kemet FM
- Radio Faza
- BAME Outreach and Development Worker for Self Help UK

The Research Team would also like to thank representatives of the wider public, voluntary and community sectors who have given up their time to contribute to the study. We are particularly grateful to members of the Research Steering Group - Rachel Illingworth, Dawn Jameson and Dr Manik Arora - for their on-going support for the study. The study had NHS research governance approval from Nottingham University Hospitals NHS Trust (Ref: 15RS004), NHS Nottingham Clinical Commissioning Group (Ref: 300615) and Nottingham CityCare Partnership.

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Introduction

This report is the main empirical output from an exploratory research study into the **uptake of primary and community diabetes and respiratory long-term conditions services in Black Asian and Minority Ethnic (BAME) communities in Nottingham City**. The study was commissioned by NHS Nottingham City Clinical Commissioning Group ('the CCG') and undertaken by a team from two research centres at Sheffield Hallam University: the Centre for Regional Economic and Social Research (CRESR) led the research with support from the Centre for Health and Social Care Research (CHSCR).

Nottingham City has a **large BAME population** which accounts for just over one third (35 per cent) of the total population, having increased from just under a fifth (19 per cent) in 2001. Although, overall, BAME residents are less likely than non-BAME residents to report poor health, this is due to the younger age profile of BAME residents, and masks an underlying trend amongst older BAME residents (aged 50+) which indicates they are **more likely than non-BAME residents of the same age to report poor health**. These trends mean long-term condition support services for these communities are important and will grow in importance in the future. As such, the CCG commissioned the study to inform how they can best work in partnership with local BAME communities to increase the uptake of community and long-term conditions services in Nottingham. In particular, they wanted to **better understand the barriers and enabling factors from the perspective of BAME communities** to support the development of effective commissioning strategies that meet their needs and promote and support increased service uptake. The study was therefore framed around four research questions:

- What are the **blocks and barriers** to people from BAME communities with long-term conditions accessing and taking up existing long-term conditions services?
- How should the CCG, GP practices and service providers **engage with BAME communities most effectively**, including through an asset-based approach?
- What **changes need to be made** to the way services are delivered?
- What are the **next steps for commissioners** to support a sustained increase in uptake of long-term conditions services by BAME communities?

The study was undertaken in two phases between April 2015 and September 2016:

Phase 1 was an evidence review, covering UK and international literature and including published academic papers and a wider body of 'grey' material from policy and practice. Secondary data were analysed to provide contextual information and to inform subsequent phases of the study.

Phase 2 involved in-depth qualitative research to explore the local context further and identify what the CCG, GP practices and service providers need to do differently to encourage increased uptake. 69 in-depth qualitative interviews were undertaken with BAME service users from across the City of Nottingham along with 17 stakeholders from the across the local NHS, its local statutory partners and the local voluntary and community sector.

This report is the outcome of Phase 2 of the research. It aims to provide the CCG and its partners with a better understanding of the barriers, enabling factors, and best practice associated with the delivery of long-term conditions services to people from BAME communities, with a view to supporting the development of workable solutions that encourage greater uptake of these services in the future. The **focus of the report is therefore in-depth qualitative findings from the perspective of service users from BAME communities** across Nottingham City, with a view to stimulating debate with the CCG and its partners about how this learning can be applied in a Nottingham City context.

The report aims to put the narratives of those that we have interviewed at the forefront of the findings using their own words wherever possible. It is structured around nine empirical chapters and a final chapter providing conclusions and recommendations:

- **Chapter 2:** Language and communication
- **Chapter 3:** Awareness and understanding of long-term conditions
- **Chapter 4:** The provision of services
- **Chapter 5:** Marketing and publicity
- **Chapter 6:** Religious and cultural issues
- **Chapter 7:** Sources of support
- **Chapter 8:** Socioeconomic status and discrimination
- **Chapter 9:** Cultural competency
- **Chapter 10:** Case studies
- **Chapter 11:** Conclusions and recommendations
- **Appendix 1:** Overview of research participants
- **Appendix 2:** Sample health leaflet.

Each empirical chapter introduces some of the key issues to emerge from Phase 1 of the research before highlighting the empirical findings from the primary data, including what they say about the barriers and enabling factors associated with each issue and the extent to which this confirms or refutes the wider evidence base.

Language and communication

Key Findings

- Poor English language skills are a significant reason for the low uptake of diabetes and respiratory conditions services by BAME people in Nottingham City.
- Participants in contact with health professionals who spoke their first language accessed services with greater ease.
- Experiences of using NHS interpreters were mainly positive and the level of service received from the interpreters was felt to be good.
- A small number of interviews highlighted a lack of consistency in the standard of service provided by interpreters. Time pressures on the interpreter to move from one appointment to the next were described as inadvertently putting pressure on a participant to rush the appointment.
- There was considerable reliance on family members to act as interpreters and translators of health information.
- All correspondence in relation to appointments, referrals and results received in English meant that a large number of participants with English literacy problems were reliant on family members to help them understand the information.

2.1. Introduction

The literature review highlighted that language is a principal barrier to the uptake of primary and community long-term conditions services by BAME communities. A number of key issues related to language were revealed: a lack of sensitivity to language differences by healthcare professionals; poor English language skills as being associated with undetected health problems (Mainous *et al.*, 2006); and the challenges of using professional interpreters (Knifton, 2012), namely, maintaining

patient confidentiality and accurately expressing patient health problems and emotions to healthcare professionals.

2.2. Language

Barriers

In line with the literature review, empirical data collected for this study reinforce that poor English language skills are a significant reason for the low uptake of diabetes and respiratory conditions services by BAME people in Nottingham City. *'She don't know how to ask (about LTC services) so that's why she don't bother to ask'* (female, 81, Chinese, diabetes): is the response received from an interpreter on behalf of a research participant in our study. Many participants reported only being able to speak and understand a little English, and only a few could read and write in English

As a result, such participants had limited understanding of their condition; how to manage it; and which services were available to help. This barrier was also substantiated by interviews with a range of healthcare professionals and representatives from voluntary and community sector organisations in Nottingham City.

One respondent shared her past experiences of seeing a doctor with whom she struggled to communicate due to language barriers. She felt that the doctor withheld information about other primary and community services that she might have been able to access for her diabetes. Her interpreter explained, *'she thinks the doctor knows she can't speak [English] so don't bother to even tell her [about other services] cos she won't understand'*. This participant also expressed concern about inconveniencing people to arrange for interpreters to accompany her to other diabetes services - *'she thinks it's too much trouble to others if she has to have interpreter to go to a group so she's just not going'* (female, 68, British Chinese, diabetes). In another example, the participant shared that rather than inconveniencing her children she would miss her GP appointment:

Because I cannot write, I cannot read English and if I trouble my children so it's better to leave it and I didn't go to see doctor (female, 78, Chinese, respiratory condition).

An area unexplored in the literature review, which surfaced repeatedly in the interviews, was concerned with the reliance on family members to act as interpreters when attending health appointments. Numerous participants' accounts convey a sense of reliance on family members to act as interpreters and translators of health information, and in a few cases there is evidence that individuals are almost completely detached from the processes related to their healthcare:

Interviewer: Because your sister goes with you [to appointments]?

Respondent: She comes with me. If I need to even phone the doctor, then my sister makes the call

I: Your sister does it?

R: I do have my own phone. But that is to talk amongst ourselves. I do not have the doctor's number?

I: You do not have the doctor's number?

R: No. (female, Pakistani, respiratory condition)

In one situation where family members and friends were unable to accompany an individual to an appointment to interpret on their behalf, a different method of communication was used - the doctor was presented with a written note. One participant explained, *'sometimes she asks her daughter to write something down and give it to the doctor.'* In this case the written communication wasn't particularly useful in helping to address the health problem because once the doctor had read the note and began to question her further she did not fully understand what she was being asked. Regardless of the communication barrier the doctor did not offer to arrange an interpreter for her. She felt so frustrated by the language barrier and her health problems not being understood that, *'she's just not bothered to go and see the doctor'* (female, 63, Chinese, diabetes and asthma).

One participant's narrative of seeing her nurse outlined how the language barrier can create a complete disconnect in understanding between the patient and health professional, and, her story of exasperation also carries a message about how a reliance on family members as interpreters might lead to information being lost during the process of interpretation:

I had told my sister, tell her what I am saying. She told her. She just said take this. That is all. I have written a prescription. When I asked my sister what had been written when we went to buy it, we found it was Paracetamol. That we already have at home! What will I do with this? (Female, Pakistani, respiratory condition)

On the whole, there were only a few negative accounts of using professional interpreters. In one example, the participant questioned the professionalism of the interpreter whom she claimed *'didn't ask her name, her information, consequently putting her off using interpreters again'* (female, 63, Chinese, diabetes and asthma).

In two other cases, the interpreters were felt to have overstepped professional boundaries by engaging in unnecessary discussion, casting doubt over the health issues of those they were representing, and making judgements about them, therefore failing to remain neutral:

What I was not happy with is that they were always asking me with appointments what my condition is and what's the issue and they were giving me advice as if they were doctors and they were telling me that it's all in my head (female, 58, Polish, COPD).

Very often I have a feeling interpreter don't translate everything I say, cos sometimes I may say quite a few sentences and he will repeat maybe half of it. Also, very often when I say something to the doctor or I reply to the doctor the interpreter is engaging conversation with me instead of, like saying 'oh really?' or doubting that it can be the case instead of being only an interpreter (female, 46, Polish, asthma).

A few participants complained about the availability of interpreters and the length of time taken to arrange for one - *'it take long time to order one, it takes a week or something'* (female, 64, British Chinese, respiratory condition). Another participant commented, *'if I need to book an interpreter sometimes I need to wait for an appointment for two weeks which is too long'* (female, 55, Polish, respiratory condition). She also emphasised the unreliability of the service; the interpreter was not always there, even though the appointment had been made in advance. Rather than risk being let down by the interpreter, the participant instead took her daughter to the appointment knowing that her daughter was less able to accurately communicate her health issues.

Time pressures on the interpreter to move from one appointment to the next were described by one participant as inadvertently putting pressure on her to rush the appointment, so much so that she would hold back from asking all the questions she had planned to ask:

Very often when we're waiting for an appointment, the interpreter who sits next to me is looking at the watch and saying 'I don't have enough time' so I feel stressed before we even get there, and very often if I have additional questions I will skip them and won't ask cos I know the translator is in a very hurry (female, 46, Polish, asthma).

A small number of interviews highlighted a lack of consistency in the standard of service provided by interpreters, as well as the level of understanding; the experience of using an interpreter depended very much on who you were assigned:

It [the experience] varied from interpreter to interpreter but on the whole I am fairly satisfied (female, 58, Polish, COPD).

They vary depending on the person (female, 46, Polish, asthma).

Some of them understand, some of them don't, that's what happens (female, age unknown, Pakistani, diabetes).

In the interviews with stakeholders, interpreters (formal and informal) were identified as playing an important intermediary role in imparting health information. The limitations of informal interpreters and the sensitivities around using them were clearly recognised, although questions were raised about the competence of some formal interpreters; in accurately relaying information, maintaining objectivity and understanding the health condition and service for which they were interpreting.

Enabling factors

Consistent with the findings of the evidence review, our research found that those participants in contact with health professionals who spoke their first language accessed services with greater ease, understood, and were satisfied with the advice and the treatment received. One participant reported, *'I'm okay, I can understand what he [the doctor] says'* (female, 73, Chinese, diabetes) and another reaffirmed that when the doctor speaks the same language as the patient, *'you can explain yourself better and you know the doctor's understood and when you've got the right medicine you feel better'* (male, 58, Pakistani, asthma). Many participants explained that they did not miss health appointments due to difficulty in speaking or writing English because their doctor was from the same, or similar, cultural background and held the necessary language skills (e.g. Cantonese, Urdu, or Punjabi). These participants talked positively about having access to healthcare professionals from diverse ethnic backgrounds. The health outcomes were also described as being positive:

I: What difference has she noticed (since changing to a Malaysian doctor)?

R: She feel a lot better, she can go herself, no need to have interpreter, she feel like she can go when she needed to (female, 68, British Chinese, diabetes).

Despite recognising, earlier, that the over-reliance on family members as interpreters for health matters could act as a barrier to an individual's comprehension of their health problem, this informal support also helped participants with language difficulties to attend health appointments. Children, spouses and siblings were all

identified as playing a significant role in attending appointments, and translating health material:

I: Has your difficulty in speaking, reading or writing English ever stopped you attending appointments for your condition?

R: Because I don't know English very well but I got some assistance from my family. So if my family is not available I will ask my friend to do some correspondence (female, 73, Chinese, diabetes).

Evidence suggests that aside from GPs arranging interpreters for their patients, in a few cases, family members proactively arranged interpreters for their parent(s) to attend health appointments. Indeed, as highlighted in the literature review, the availability and accessibility of professional interpreters plays a significant role in imparting health information and raising awareness of the services that exist in the community to manage specific conditions.

The majority of participants' accounts of using professional interpreters contradicted the assertions in the evidence review about patient concern around their confidentiality being compromised and interpreters not being able to accurately convey their emotions.

In the main, experiences of using NHS interpreters were positive and the level of service received from the interpreters was felt to be good. Commenting on this, one participant said, *'of course interpreter is very helpful because he give me the explanations'* (male, 81, Chinese, diabetes), and another participant stated, *'the interpreter give me a lot of assistance'* (female, 78, Chinese, respiratory condition). A good level of trust in the interpreter was conveyed, in that he/she was able to relay information precisely:

Whatever I tell the interpreter she tells the nurse and vice versa. The interpreter in turn explains it to me (female, Pakistani, diabetes).

I: And you trust that whatever you tell them, they accurately tell your nurse or at hospital?

R: Absolutely yes.

I: And you feel that whatever you share will be kept in confidence?

R: Yes absolutely (female, 42, Pakistani, diabetes).

Although one participant's narrative describes a negative experience of using an interpreter many years ago when she newly arrived in the country, she goes on to express how her experience of using this service has improved considerably since then:

I was in hospital when I had my first daughter and I didn't trust the interpreter then and she didn't explain my thoughts properly... that interpreter didn't help me at all. She didn't even tell me what was halal... Then when I went to my GP I met an interpreter there and she's so nice and I trusted her so much (female, 38, Pakistani, diabetes).

2.3. Correspondence related to health

Barriers

..... All correspondence in relation to appointments, referrals and results was received in English meaning that a large number of participants with English literacy problems were reliant on family members to help them understand the information:

Sometimes I ask my daughter to read (male, 72, Chinese, diabetes).

.....
My son will explain to me the English correspondence. My son will arrange everything, will tell me when is the time to see the appointment (male, 81, Chinese, diabetes).

.....
I ask one of my family members to read it and they explain it to me, as I cannot completely understand English (female, Pakistani, diabetes).

.....
Her husband read for her. She said I eat loads of medicine, I don't know even the name [of the medicine], my husband reads (female, 55, Pakistani, diabetes).

The last example conveyed powerfully just how little the participant knew about her health condition, and how detached she was from managing it due to difficulties with literacy. Evidence from the review suggested that those who knew little about their condition and how to manage it were less likely to engage with services for managing their condition.

Enabling factors

Besides receiving support from family to understand health related correspondence in English, evidence suggests that local community organisations such as the Chinese Welfare Association and the Asian Women's Project play a vital advocacy role, including helping individuals to make sense of correspondence:

Sometimes come in here [Nottingham Chinese Welfare Association] (male, 72, Chinese, diabetes).

.....
I get those read for me or I get them read at the centre where I go to do my prayers (female, 60, Pakistani, diabetes).

I sometimes come to this office (Polish?) to information sessions to request for the letter to be translated (female, 46, Polish, asthma).

Awareness and understanding of long-term conditions

Key Findings

- There was a significant knowledge gap around the symptoms and management of both diabetes and asthma.
- Where gaps in knowledge existed, some participants explained this was due to a lack of available information, both at the point of diagnosis and subsequently.
- Participants had more confidence in managing their condition where they had attended diabetes educational courses – such as Juggle – or had engaged with a specialist diabetes nurse and/or a GP.
- Other useful channels for learning about a health condition, included self-research (via books and the internet); television; community radio; and leaflets/health pamphlets.

3.1. Introduction

A review of the literature found that, amongst other factors, a lack of baseline knowledge and awareness of a health condition and its significance acts as a considerable deterrent to seeking medical advice and treatment in the first place. A lack of adequate channels of learning and education, which are tailored to a particular BAME community, means that patients may fail to even recognise their symptoms or connect them to a particular condition (Chowbey *et al.*, 2008; Gerrish, Ismail and Naisby, 2010).

Exploratory studies have revealed a knowledge gap about the causes, symptoms and management of diabetes among particular populations (Råberg Kjøllesdal *et al.*, 2011 looked at perceptions of risk factors among Pakistani immigrant women, for instance). In relation to awareness around eating disorders it was the younger generations who tended to be more informed (via school and the media) than older first-generation migrants. A lack of awareness can also exist in relation to the kind of health services on offer in the community. This was also structured by age, with those older and less mobile being less likely to notice services or their

advertisements through not physically walking past them, or being socially isolated and having fewer social connections within the community (Chowbey *et al.*, 2008).

There remains a risk of conditions being under-reported and 'hidden' among BAME groups unless further efforts are made to reach communities at the earliest opportunity.

3.2. Barriers

A significant knowledge gap, around the symptoms and management of both diabetes and asthma, was evident from the interviews. Many participants admitted to knowing nothing or very little about their condition.

I: Can you tell me how much you know about your diabetes?

R: Not much, just a little (female, 38, Pakistani, diabetes).

I: How much do you feel you know about your condition? Have you gained any knowledge from it elsewhere, whether it's researching it yourself from leaflets or the internet?

R: No, nothing at all (female, 49, Pakistani, asthma).

I: So you seem to know very little about how to manage your diabetes?

R: I don't know at all, I don't know how to control it (female, 38, Pakistani, diabetes).

I: What do you know about diabetes?

R: At this stage I don't know anything about it (female, 42, Pakistani, diabetes).

I: Does she know about the food she's allowed to eat?

R: She doesn't have any idea [...] she never thinks about it (female, 55, Pakistani, diabetes).

I: How much do you feel you know about your diabetes? Do you feel you know enough about it or are there any gaps in your knowledge?

R: I'd say I wouldn't know enough about it (female, 55, Pakistani, diabetes).

I: How much do you feel you know about diabetes?

R: Not a lot really, I don't think so anyway (female, 80, African Caribbean, diabetes).

I: How much do you know about your condition?

R: I don't know that much. I know it's a long-term illness and I'll have to take medicine all my life (female, 46, Polish, asthma).

Other participants had a limited, basic grasp of their symptoms but could not explain why they were occurring or how to better self-manage and control them. For example, one participant who did not know much about the symptoms of her diabetes admitted that much of it was 'guesswork' (female, 55, Black British, diabetes and asthma). There was even an expectation that the symptoms and effects of their condition would be something participants would learn as they were exposed to those aspects of the condition. For example, one participant knew that asthma meant she 'struggled to breathe sometimes but that's it' (parent of female, 14, Polish, asthma).

A number of participants explained their condition through their own lens and self-diagnosis:

She just thinks it's a lottery illness [...] because you have a lottery in life so that's what's causing it (female, 68, British Chinese, diabetes).

The disease has come from god and I trust and I don't complain about this (male, Pakistani, diabetes).

She can definitely feel the changes in her body when it's high, even without checking (female, 66, Bangladeshi, diabetes).

I also believe in herbal medicine and I travel to the Caribbean a great deal so I've developed my own way of drinking certain natural remedies to help my diabetes (female, 63, African Caribbean, diabetes).

R: I have controlled it. Drink warm water, don't drink cold liquids.

I: Who told you this?

R: I, myself. Nobody has told me this (female, Pakistani, diabetes).

Feeling satisfied that they already had all the knowledge about their condition held some participants back from attending the Juggle Diabetes Service or engaging with other services:

I: Why wouldn't you go [to the Juggle Diabetes Service]?

R: Because this is the thing I know about, I feel what I'm doing is okay. Like in the middle of the night I wake up sweating and I know I must get up and eat something – milk, sometimes two pints of milk, and bread and butter and jam [...] so I know about this knowledge, what to eat (female, 69, Indian/Kenyan, diabetes).

They sent me a letter for some open day in town but I never went cos I know what I'm doing, if I need anything I just research it on the internet (female, 26, White/Pakistani, diabetes).

This, for some, meant that their condition had been managed incorrectly for a period of time. A mother, talking on behalf of her 14 year old daughter who suffered with asthma, told the interviewer that her heartbeat accelerated when she overused the inhaler. Due to a lack of understanding or any alternative when feeling like she is struggling to breathe, she '*just keeps using the inhaler again and again*' (parent of female, 14, Pakistani, asthma). Similarly, another participant had themselves suffered with asthma for 18 years but had only recently learnt how to use the inhaler correctly for her daughter:

I wasn't told that every puff that I give her I need to take the inhaler back out, shake it, put it back in again, and when you do it with a mask it's quite a big job cos the child gets fidgety [...] so I would hold the mask to her face and just keep pressing it and they told me that actually she's getting half the dose by you doing that (female, 28, Bangladeshi, asthma, talking about her daughter)

Another participant had recently moved to Nottingham City and had not at the time become aware of the diabetes services in the area, and was sceptical about receiving any help. Because of this lack of engagement, the participant was struggling to administer his medication correctly:

R: Even now I don't know how to use the machine to check the blood glucose

I: Sometimes he's very tired or has low energy and will take the wrong medicines (male, 72, Chinese, diabetes).

Often with this lack of understanding about the condition and its management came a sense of helplessness, of not knowing what else to do:

I: So how much do you know about your diabetes?

R: Just that when you feel bad then you take tablets, what else can I do? (female, 60, Pakistani, diabetes).

Some of the participants contradicted the assertions in the literature regarding a low level of knowledge and awareness around diabetes. This cohort included participants who had been living with diabetes for a long time and had learnt how to manage it through practice:

I know quite a bit about both of them because I've had them for quite a while (male, 64, Pakistani, diabetes and asthma).

It's been so long it's okay for me now (male, 65, Pakistani, asthma).

I'm more aware of it than before, for the asthma, I'm so used to it (female, African, asthma).

It also included those with a family history of diabetes, who were familiar with the symptoms and management as a result; those who had worked in the health profession (though this participant stressed the importance of up-to-date refresher courses); and people who had engaged more readily with health professionals and the educational courses in Nottingham City (covered in more detail in the following sub-section on enabling factors).

Where gaps in knowledge existed, some participants explained this was due a lack of available information:

I: How much do you feel you know about your condition? Do you think there are any gaps in your knowledge?

R: I think it's 50/50, I think I could know more but you don't get all the information (female, 30, Pakistani, diabetes).

They need more refresher courses, you have to have it refreshed, not going through all the basic things [...] I think more refresher things are needed (female, 41, Pakistani, diabetes and asthma).

I: When she goes to see her doctor is she given any leaflets about asthma, what it is, what the symptoms are, this is what you can do to manage it?

R: No, nothing.

I: Do you need anything like this, do you require more information?

R: Yes, I should be able to find out more, to find out anything else beyond the use of inhalers, anything extra (female, 35, Pakistani - on behalf of daughter, 14, asthma).

They teach people with diabetes about their options, people who have blood pressure, they say eat this, don't eat that. My father-in-law has diabetes and

blood pressure and the doctor recommends what he should eat, what he shouldn't eat, but for asthma they don't do anything (female, 35, Pakistani - on behalf of daughter, 14, asthma).

[...] there is no-one to tell you, why it's happening, the doctor don't explain when you go see them, they've only got 10 minutes (female, 70, Indian, asthma).

I haven't done any groups or any programme and I've never been told to do it so I don't know about it (female, 67, Pakistani, diabetes).

Other barriers to understanding their condition and engagement with services included a sense of reluctance and fear, on the part of the participant, of confronting the reality of their condition. This was notable for a participant diagnosed with COPD:

I didn't read much about what COPD is, and that's related to my depression. When I start reading about it I get worried and I start thinking that I'm in very bad condition and it makes me worse (female, 58, Polish, COPD).

Evidence from the stakeholder interviews suggests that there is a lack of awareness amongst key voluntary and community sector organisations of the long-term conditions services available in Nottingham City, and even a lack of awareness amongst health professionals about the specific long-term conditions services that they can refer patients to:

I know they (LTC services) have existed but if they still exist now they're probably smaller scale than they have been in the past (Voluntary and Community Sector Stakeholder).

3.3. Enabling factors

As might be expected, participants had more confidence in managing their condition where they had attended the diabetes educational courses in Nottingham City or had engaged with a specialist diabetes nurse and/or a GP.

I know more or less all about it cos I had Juggle Diabetes Service and the GP keeps you updated (female, 30, Pakistani, diabetes and asthma).

I: Do you understand your symptoms?

R: Yes I understand those. A woman came here and she was telling us 'eat less sugary foods'. That was about a year ago, she told us everything (female, 60, Pakistani, diabetes).

The Juggle Diabetes Service was cited as being helpful and informative on several occasions:

He knows all about his disease, how he can control it, but that seminar was really helpful, they explain everything, how you can control, how the medicine can work on your sugar level, so he learnt a lot (male, 58, Pakistani, diabetes).

I didn't know about it before. But after I did this course I found out that this is a very dangerous disease (male, Pakistani, diabetes).

I: Did it help you [attending Juggle]?

R: Yeah

I: What did you learn?

R: They tell you healthy eating, not eating fatty food (female, 53, Pakistani, diabetes).

Often attending the Juggle Diabetes Service and engaging with a diabetes nurse had changed people's behaviour:

Before this, I used to use a lot of sugar and salt. Now I try to use a sweetener. I eat less sugar (male, age unknown, Pakistani, diabetes).

I don't have white bread anymore, I have wholemeal and I don't have much of that. I've lost a bit of weight actually... five fruits or veg a day since I became diabetic. I took that on from the nurse cos I had a really good nurse and she used to tell me lots of things (female, 61, Black Caribbean, diabetes).

I've started walking, I've cut out sugary foods altogether (female, 42, Pakistani, diabetes).

Other channels, cited as being useful in terms of learning about a health condition, included self-research (via books and the internet); television; community radio; and leaflets/health pamphlets. It was fairly commonplace for participants to engage with a combination of media to learn about their condition:

I did my programme on diabetes [...] somebody asked me to do it so I did it. So I have got not 100 per cent knowledge but say 60 per cent [...] I read the books from the library for my programme and I used to see how my mother used to treat everybody and since I've got it now I see how the doctors and nurses treat me (female, 67, Pakistani, diabetes).

Several potential areas for improvement to information provision came up in the course of interviewing. One suggestion was to begin information provision, education, and intervention at an earlier stage before the onset of diabetes.

I think the doctor only tells you when the sugar get to level 1, level 2, when it gets to the end, that's when the doctors take notice, that's when they say 'no, stop eating that' (female, 38, Pakistani, diabetes).

When my doctor told me early on I didn't know enough about diabetes. If I'd had awareness early on I would have controlled it [...] I regret the fact that if I'd known earlier I would have controlled it better. When I was properly diagnosed as having diabetes, that's when the nurse told me I had full-fledged diabetes (female, 61, Pakistani, diabetes).

Provision of services

Key Findings

- Interviews revealed a mixed level of patient satisfaction with the flexibility and convenience of appointment times and locations for long-term conditions services and educational programmes. While some participants spoke positively about their experience of making an appointment, others encountered difficulties with the appointment booking systems at their local surgeries.
- Participants were keen to attend educational classes but struggled to travel there if they were not within easy reach of their homes.
- Long-term conditions services were more readily taken up when the appointment times fit in with the daily work, family, and other commitments of patients.
- Continuity of staff made a difference to patient satisfaction and willingness to engage with a long-term conditions service.
- Participants spoke positively about long-term conditions services where they had been attentive to specific cultural needs.

4.1. Introduction

In the evidence review we identified a number of barriers to uptake of primary and community health services which revolved around cultural appropriateness (how well services meet cultural needs); location and proximity of services to the community as well as opening times; and cost (of transport, medication, and entrance to leisure facilities/classes). Research has found that some BAME groups are reluctant to access facilities outside of their local communities, especially those that are costly (this includes the cost of travel to the facility), and that health education should acknowledge the 'limited resources and facilities available to people at community level' (Chowbey *et al.*, 2008: 34). The ability of services to meet cultural needs is recognised as significant to uptake (having prayer facilities and women-only spaces in gyms, for instance). Chowbey *et al.* (2008) noted how smaller BAME communities can be unintentionally excluded if the majority of resources are directed to the larger and more visible BAME community: 'when people from less visible BAME communities are in contact with services they encounter the additional barrier of service providers lacking an awareness of their specific culture, needs, and expectations' (Bamonte *et al.*, 2015: 18). Time (availability of appointments, length of

educational programmes) can also make a difference. Previous research has linked high levels of drop-out from an educational programme with the length of the intervention (completions increased when a six-session intervention was reduced to a one-day workshop).

This same body of literature contained several recommendations, or 'enabling factors', around service provision for reaching BAME communities who are not engaging with services. This included outreach work which links with key community organisations and stakeholders who have experience and expertise in working with minority ethnic groups. Outreach work has been shown to raise awareness of services; raise the profile of long-term conditions services; help to shape the services according to need; and change attitudes towards long-term conditions.

Patient involvement, or the ability for patients to have a say in how services are run, is acknowledged in the literature as a way of increasing uptake of services. Giving patients 'a voice' in the planning and delivery of health services and their treatment plan is likely to lead to more empowered, informed and engaged patients.

4.2. Times and locations of health services

Barriers

Interviews revealed a mixed level of patient satisfaction with the flexibility and convenience of appointment times and locations for diabetes services and educational programmes. While some participants spoke positively about their experience of making an appointment with their diabetes nurse or GP, others recounted the difficulty of booking an appointment (and actually getting one). Several participants had encountered difficulties with the appointment booking systems at their local surgeries.

It's very difficult to book an appointment. You have 15 minutes' chance to ring reception at 8 o'clock, and you start ringing, no answer, so you go down, book the appointment and sometimes they say come back at 9 o'clock, 9:30, cos you can't get through if you phone (female, 67, Chinese, diabetes).

It takes so long to book the doctor (female, 64, British Chinese, respiratory condition).

In the morning it's really busy cos you've got to phone 8 till 9 and in that time I try 100 times sometimes, I get really fed up and then all the appointments are going (female, 49, Pakistani, asthma).

I haven't seen my nurse, I saw her on December 10th 2015. Since then I haven't seen my GP cos I can't get an appointment (female, 38, Pakistani, diabetes).

Before he got an appointment after one or two days but now it's one week, more than one week (male, 58, Pakistani, diabetes).

Sometimes when you're feeling ill this system where you've got to get up in the morning, get washed and ready, phone the doctor's for half 8 just to get an appointment, sometimes just getting an appointment it's really hard (female, 55, Black British, diabetes and asthma).

Quite often reception seem to think they've got a doctor's degree and they want to tell you what the problem is without you seeing the professional or you'll get a lot of ignorant comments like 'why don't you go to this service instead, like A&E

or the walk-in centre?' My response is 'you're my primary carer and my first point of contact and I need help now'. So it's not the GPs, it's the person in between us that can cause the problem (female, 28, Bangladeshi, asthma).

The unsuitability of surgery and clinic opening hours/days, and the inflexibility of services, was acknowledged as a potential area for improvement in the stakeholder interviews:

When you look at the way the clinics are set up, say 8-5 or 8-6 depending on the GP practice, and if you have someone who's going to work, they can't leave work between those hours so they're likely to miss their appointment, some people work Monday to Friday and would like to be seen at a weekend, some employers would give time off to attend the clinics, and some won't so they'll end up missing their appointments.

Participants also struggled to attend other health and fitness services in the community if they could not fit them into their daily schedules.

Especially if you're a single parent and you've got other commitments, you're spending more time in the travel than benefitting on what is available and you have limited times for these things (female, 41, Pakistani, borderline diabetes and asthma).

I had a weight management lady come before but I think they've stopped that now, but they were giving me options like walk around but it's hard cos they only give you certain times that you can go and when you have a child and your mum it's hard (female, 30, Pakistani, diabetes).

I: What role, if any, do self-help groups play in helping you to manage diabetes? Have you ever been to a self-help group with maybe women-only there talking about diabetes and sharing their experiences?

R: She's never been to any. No, she's been twice or three times but then she stopped cos she had to rely on dad to take her early mornings and they're not early morning people (female, 66, Bangladeshi, diabetes).

Where participants were unable to attend appointments and take up diabetes services - largely due to work and family commitments - there was evidence of them trying to manage their conditions themselves. One participant, who had been diagnosed with asthma, worked full-time and could only make evening appointments. She told us:

I have to try and make appointments fit in around work, so maybe evenings or something. Sometimes the surgery's busy and they can't fit me in. If I'm not feeling well I'd try and manage myself rather than go to the doctor's straight away I suppose [...] I use my inhalers and keep my chest warm and try and avoid getting a cold and things like that. So I do feel I'm able to manage my health (female, 48, Black African Caribbean, asthma).

Often, participants were keen to attend classes but struggled to travel to services if they were not within easy reach of their homes. Some participants would have attended classes if they were offered help with travel. This was a particular barrier in cultures where women could not leave the house and travel to services alone.

The times or the places are really far. I think they had a few cooking classes, I was really interested in them but they're really far away from me (female, 30, Pakistani, diabetes).

R: When you're suffering you've got to do it, you don't have a choice. And the taxis are very expensive.

I: What would you like to see improved to make it easier?

R: To get help to get to the doctor when I'm really ill (female, 49, Pakistani, asthma).

Sometimes I am late by 2 minutes; sometimes it takes time to catch a bus. But in X, even if you are late even by 5-10 minutes they cancel the appointment. They tell us to fix another appointment. This is what happens, nothing else (female, Pakistani, diabetes).

I: What does she think about the time and location of routine health appointments?

R: It's difficult, her GP is in town centre, that's not very close so that's not convenient, she has to travel to town (female, 53, African, asthma).

For people who can't come out, cos that can be a problem in some cultures, maybe going to them [would help]. For example my daughter has really bad allergies so I had a lovely nurse who came out and she trained us with the EpiPen (female, 28, Bangladeshi, asthma).

In certain cases, participants were still registered with GPs closer to their previous addresses, and were not aware of other services within easier reach.

The GP practice I'm registered with is the first one I've registered with after my arrival and I never changed it even though it's longer distance now. There are community services nearer to my house but I don't use them cos I'm not quite sure what's there (female, 46, Polish, asthma).

Enabling factors

There are a number of obvious enabling factors to emerge as responses to the barriers experienced by participants in relation to times and locations of health services, as outlined above. First, health services were more readily taken up when the appointment times available fit in with the daily work, family, and other commitments of patients. This could be combined with a flexible and understanding approach by health professionals and the health administrators (receptionists, secretaries etc.) who often act as 'gatekeepers' to appointments.

Participants noted the flexibility of appointment times which they could easily fit around their daily routines and commitments.

I: In terms of the times you're given for appointments to see your nurse for example, do those times suit you?

R: They ask what time suits and give you an appointment straight away (female, 42, Pakistani, diabetes).

They are flexible 'cause if I want to change they always allow me to change (female, 41, Pakistani, diabetes).

The surgery's open from 9 till about 6 or 6:30 so I can get an appointment after work (female, 48, Black African Caribbean, asthma).

I: How well have the times and locations of the primary and community health services fitted in with your daily routine and commitments?

R: They've been really good, they've been able to do the appointments after my work times or during holidays (parent of male, 8, Bangladeshi, asthma).

Flexibility and accessibility of services was emphasised by a number of healthcare providers, in the stakeholder interviews, in terms of providing out of hours access, at different venues, flexible opening times and where necessary taking services directly to the targeted communities:

In general having flexible appointment times that people can attend, convenient locations, we have a triage nurse on every day who responds to phone calls if anybody's got any problems, having a visible, accessible service.

The appointment booking system itself frequently stood in the way of patients engaging with long-term conditions services. To book an appointment at their doctor's surgery, participants spoke about having to go through the standard telephone booking process, often so busy that patients gave up at the first hurdle. Offering diabetic and asthmatic patients an alternative route to booking appointments, or making them more aware of an existing one, may help to address this barrier. A similar approach would perhaps benefit the uptake of educational programmes and related health services in the community: expanding the times available and offering slots for those with child and other caring commitments. We came across examples of good practice where patients had the opportunity to contact their specialist nurse directly, if any problems arose.

Continuity of staff made a difference to patient satisfaction and willingness to engage with a healthcare service. Seeing the same healthcare professional on each appointment fostered a greater sense of rapport and trust, and allowed the patient to tell their 'story' more openly, and on just one occasion.

In terms of service locations, it worked better when they were located within the community and were easily accessible to target groups. Proximity of health services did not come up as an issue for all participants; indeed some gave positive feedback of how conveniently they were located.

I: Do you feel the locations of health services, are there enough of them?

R: I think they're quite good cos they've got free parking with them and they're local as well (female, 30, Pakistani, diabetes and asthma).

I: In terms of the timing and location of primary health services like your GP, how does that fit in with your daily routine?

R: Pretty well, it's quite local so I can walk there and it's also on a bus route... (female, 48, Black African Caribbean, asthma).

There's always something nearby. Juggle was in the Meadows as well, I didn't have to go far [...] The GP is down there as well so it's not far (female, 55, Black British, diabetes and asthma).

I feel for her lifestyle she's quite happy the way things are. It's within walking distance so she can easily go there and come back for prayers (female, 66, Bangladeshi, diabetes).

Participants missed out on attending services or related activities which would have been beneficial to their diabetes management because they could not physically get there. In such a sense, patients' access to free community transport or an increase in outreach work may help to increase the uptake of primary and community health services.

4.3. Services meeting cultural needs

Barriers

In the main, participants were happy with how health services catered for their cultural and/or religious needs. Where barriers existed they tended to be around a lack of understanding of food/diet for a particular culture on the part of the health service. In one case, this involved a diabetes nurse suggesting that a patient breaks their fast for health reasons:

I was fasting and I happened to go to the clinic so I had a test and the diabetic nurse said to me I needed to open my fast, I shouldn't be doing it because health-wise it wasn't advisable. So I thought 'yeah, I had to keep to what they were saying'. But I think if it was somebody that had a similar culture they would possibly understand and possibly support me in terms of keeping the fast, attempting to do it for a number of hours or so (male, 40s, African, diabetes).

Patients expressed a preference for healthcare professionals who were of a similar culture, so that cultural needs around diet and food would be better understood. A British African participant with Type 2 diabetes explained the importance of food, culturally, and how difficult it can be to explain diet to a healthcare professional outside of that culture:

If you're BAME you have quite a lot of salt intake and we use quite a lot of certain oils and spices and stuff like that, so for somebody not understanding some of these – the quantities one has to use – it's very difficult for them to advise you professionally (male, 40s, African, diabetes).

A similar issue was encountered by a participant who had attended an educational programme on diabetes. Dietary advice given in the class was generic rather than tailored to a specific (in this case, Bangladeshi) culture, which at times was of little relevance to her:

It wasn't specific to their diet, it was just general, like you can have meat but once a week and less oil when you cook, fish but cooked in a different way (female, 66, Bangladeshi, diabetes).

A mother, speaking on behalf of her son (aged 8) who had been diagnosed with asthma, found the timing of women-only swimming classes problematic when trying to follow advice from her GP that swimming would help her son's condition: *'it was very limited because the women's sessions were in the daytime so I couldn't take him after school [...] I had to wait till after school but then it wasn't women's time, so that I struggled with'* (parent of male, 8, Bangladeshi, asthma).

Enabling factors

Where participants spoke positively about the health services they had received it was because they had been attentive to specific cultural needs. Recurring examples of this included leisure and sports facilities that ran women-only sessions:

They've started doing women-only swimming sessions and women-only sessions for the sauna. And the downstairs gym here, the ladies-only gym, and there's one up the road that's quite good, they do personal training and everything (female, 30, Pakistani, diabetes and asthma).

I didn't go to the gym before but I used to go for a walk early in the morning and then do exercise at home but the gym is for women only and it's good for me (female, age unknown, Pakistani, diabetes).

As mentioned earlier in Section 2.3, participants were more satisfied and engaged with services where they met language needs by offering interpreters or if the health professional spoke in the participant's first language. As one participant commented about the Juggle Diabetes Service, *'she was explaining it in English and in our own language'* (female, age unknown, Pakistani, diabetes). In the stakeholder interviews, Juggle was repeatedly given as an example of tailored provision whereby language needs, reminder telephone calls, design of resources, the level of education are all carefully considered to meet the specific needs of the groups the programme serves:

It's [the Juggle programme] pitched at all levels of language and literacy, we're putting across very complicated information about diabetes management in a very simple format, we use lots of visual aids, lots of pictures, we've got minimal written information in our presentations, it's not IT based, it's all hands on, food models, displays with big pictures that very easily explain the process of digestion and what diabetes is.

Similarly, participants felt that their cultural needs were better understood when the health professional was from a similar background: *'the doctor is from a similar background to us, the Indian woman we go to, sometimes my back hurts but she'll do the check and I'm happy about that'* (female, Pakistani, diabetes). Where health services actively made provisions for cultural and religious dietary requirements this was also viewed favourably by participants. As one participant said *'when I was in hospital they asked me if I'm Muslim and they used to be very careful about the food and provide halal food so that's quite good'* (male, 65, Pakistani, asthma). Another participant mentioned how the diabetes educational programme leader had considered their cultural food choices and had tailored aspects of the sessions and the course materials around this: *'They had asked about our food type and included it in the information given how to manage'* (male, Pakistani, diabetes).

4.4. Patient involvement in service delivery

Barriers

The importance of patient involvement and feedback in service delivery was acknowledged by participants:

You should be able to speak your feelings to them (female, 69, Indian/Kenyan, diabetes).

Yes, I would do that. I would always say what I feel (female, 37, Pakistani, diabetes).

If there was something that I do not like, I will definitely go and say that you have not done this thing right, you are doing this wrong (male, Pakistani, diabetes).

I think they [the patient] should have the biggest say cos they're the one who the illness is with, they should have at least some part in it (female, 61, Black British, diabetes).

One participant stated that the doctor-patient interaction should work both ways and just as the patient listens to the doctor's advice, so too should the doctor listen to the patient's feedback: *'It's very important, some of their advice we should take heed of and some of ours they should hear'* (female, 38, Pakistani, diabetes). The aspects of service delivery about which participants wished to be consulted ranged from the location of the service; the language skills of staff; and patients' needs in general. Although participants were of the general impression that patients were being increasingly consulted on service delivery, the majority had neither been involved in a public consultation nor had they been approached to take part in one:

R: I think they get better day-by-day, they're doing more than they used to do.

I: So people are consulted?

R: Yeah

I: Have you ever been involved in any consultation?

R: No (male, 65, Pakistani, asthma).

If I was approached I would give a say but I've never been in that situation (female, 26, White/Pakistani, diabetes).

Indeed, some participants did not know (or had not been made aware) that they were able to 'have a say' at all. On the one hand this was because they had so far encountered no reason to provide feedback because they were satisfied with how the service was run; in other cases, it was because they had not been made aware that they could have a say. In several cases, participants were unaware of the mechanisms that they would have to go through to be able to make themselves heard.

I: How important is it that patients are able to influence how health services are designed and run?

R: I've never thought about it.

I: Are you pleased with how they're currently run?

R: Yeah, I'm pleased with how they're running (female, 61, Pakistani, diabetes).

R: No, actually, I don't know where to go. If they can't help me I don't know where to go (female, 69, Indian/Kenyan, diabetes).

Being able to voice concerns and 'have a say' requires a degree of confidence. In many cases this was undermined by fear and distrust in the system (i.e. that their concerns would not 'go anywhere') which had led to a sense of apathy. This fear was sometimes rooted in past experiences where the patient had felt they had been 'let

down'. Some participants were afraid to 'rock the boat', and in one case, that complaining may result in not getting an appointment at all.

People fear making a complaint, like my parents if they're treated badly will say 'we'll never complain, if we complain we'll never get an appointment' (female, 41, Pakistani, borderline diabetes and asthma).

You don't know if it's going to make an effect on them or not (female, 30, Pakistani, diabetes).

If I felt I wanted to say something I would, but I don't know how much notice anybody would take (female, 37, Pakistani, diabetes).

You can keep going to the doctors and complaining and eventually they'll try and make certain changes but you have to make a nuisance of yourself [...] you don't want to come across as being rude or upset your doctors so you don't say anything (female, 55, Black British, diabetes and asthma).

Politics is more being part of these health systems, any government changes, this and that [...] but that's not in our hands, it's in the hands of politicians (female, 79, Indian Punjabi, diabetes).

I don't feel like I had a platform to stand on and say this is wrong [...] I had a haematoma and there was this complaints service called Pals at the hospital which lost my complaint [...] That makes me think there's not really a complaints system [...] it doesn't matter if you complain, it's not going to get heard (female, 28, Bangladeshi, asthma).

Enabling factors

Participants stressed the value of outreach work which engages with communities directly and face-to-face, and where there is an opportunity for patients to ask any questions and for clarification. This is especially important for communities where levels of low literacy exist in both English and first languages (and given some dialects, such as Mirpuri, are only spoken). As participants explained:

You might post a leaflet and they haven't got time to read or whatever or they can't read it or if it's in Urdu, Punjabi isn't really written, it's mainly spoken (female, 64, Pakistani, asthma).

Well you mentioned outreach workers. Maybe if there were outreach workers we could feed into, our opinions and they can pass it up to the relevant people maybe (female, 48, Black African Caribbean, asthma).

I: What's the best way to make people from your community aware of this, when they do it?

R: Just to meet them and talk to them like we did today (female, African, asthma).

Outreach workers, or community workers acting on behalf of specific BAME groups, may also help to allay any underlying fear or suspicions which act as barriers to patients being involved in the shaping of health services. Communities may feel safer voicing their concerns to a trusted community worker who can act as an advocate on their behalf.

Marketing and publicity

Key Findings

- The interviews revealed that translated health information (e.g. leaflets, booklets) on diabetes and respiratory conditions was not offered to the majority of the BAME research participants involved in our study in their main languages.
- However, translated materials proved ineffective where patients were illiterate in their first language and health materials alone were not seen as enough to convey complex health information.
- Face-to-face contact, including the Juggle Diabetes Service, along with outreach workers, and speaking with others living with that condition, was a valued method of learning about the management of long-term conditions for many participants.

5.1. Introduction

The appropriateness of health information for ethnic minorities was identified as another barrier in the literature on the low uptake of long-term conditions services. The drawbacks of communicating health information and raising awareness via translated publicity materials were noted in the evidence review. Common barriers included: materials printed in the English language and unavailable in translated formats; cryptic, subtle and indirect wording; failure to include multi-racial images; little attention paid to advertising through press, radio and television stations, and other alternative channels. Media, such as community radio and audio/visual recordings, were recognised in the evidence review as a more effective alternative to be used alongside, or instead of, written materials (Chowbey *et al.*, 2008).

Written media - even if translated - may exclude harder-to-reach or seldom heard groups within BAME communities who may be illiterate in their first language - and these are the groups who are likely to have a greater need for health information. Where health material is used, it should be accessible and digestible; reflective and representative of the community the service aims to serve; and should draw on testimonials from BAME service users to convey the inclusivity of health services.

5.2. Receipt of health information

Barriers

The interviews revealed that translated health information (e.g. leaflets, booklets) on diabetes and respiratory conditions was not offered to the majority of the BAME research participants involved in our study in their main languages (or sometimes, at all). Participants commented on the general lack of health materials and would have liked to have been offered more as a way of finding out more about their diabetes or respiratory condition.

I: Do you currently receive any health information about asthma, any leaflets or anything?

R: No

I: Would you like that?

R: Yes, I would. I've got hypertension as well. I'd like that information as well.

(female, 49, Pakistani, asthma).

I: How do you receive health information about your respiratory condition, if at all?

R: I go to the doctor with my daughter and that's it (female, 55, Polish, respiratory condition).

I: I would only remember maybe one occasion and it was probably in hospital, no sorry, in GP surgery and it was just there. I went to it myself; it wasn't given to me (female, 28, Bangladeshi, asthma).

I'm quite sure there's lots of research taking place and if there are any changes in terms of maybe new medication on the market that someone might want to try, I'm very interested (female, 63, African Caribbean, diabetes).

Similarly problematic was where health information was given to patients untranslated, not in the patient's first language.

R: There is no Chinese version of the leaflet.

I: Would you have liked that information in your language?

R: Yes, if there is some (female, 68, British Chinese, diabetes),

R: The nurse gave me only one book at the start, that's it.

I: Was that in her own language or English?

R: English.

I: Who translated it for her?

R: Her husband (female, 55, Pakistani, diabetes),

However, as argued in the literature, sometimes translated materials proved ineffective where patients were illiterate in their first language. A Chinese participant with low literacy levels in English and in her first language (Cantonese) explained that translated material would prove useless due to her inability to read and write in Cantonese (female, 81, Chinese, diabetes). Likewise, as another participant explained, *'even if I receive in Chinese my son cannot read Chinese, my daughter*

cannot read Chinese' (female, 78, Chinese, respiratory condition). Another participant, who had been sent leaflets on managing diabetes through the post, was asked:

I: Do you understand the information?

R: No my daughter looks at it for me (female, 60, Pakistani, diabetes).

'I'd have to ask someone to read it for me' (female, Pakistani, diabetes) - in another example, a participant with low literacy skills in English and Urdu emphasised her reliance on other people to translate health materials; her daughter to translate English materials and others to translate the Urdu materials, due to her daughter's inability to read and write in Urdu. As a speaker of the Mirpuri dialect, which is spoken but not written, Urdu - the national spoken and written language of Pakistan - was as much a language barrier to her as English. Where there was a reliance on other people to translate the material, individuals were waiting some time before the information was explained to them, and this was reiterated in two accounts:

She gave me a leaflet and I did say to her that I would ask my friend to read it to me so I'd know what it said (female, 42, Pakistani, diabetes).

I can't understand English but I did ask what should I eat, what shouldn't I eat, I've been asking others to get some of the leaflets read (female, 60, Pakistani, diabetes).

Other participants commented on the content of the health materials; and how they would have liked to have seen a greater variety of information, *'sometimes you already know and it's just the same things coming again and again'* (female, 26, White/Pakistani, diabetes). Health materials alone were not seen as enough to convey complex health information. As one participant commented, *'the information they give you is okay but sometimes you need more explanation as well. Leaflets may not tell you everything'* (female, African, asthma).

Enabling factors

We asked participants about what would work best in terms of helping to raise their awareness and understanding of their condition, and encourage them to take up health services. For some, the availability of health information in written form was felt to enhance basic knowledge of the specific condition as well as supporting the management of it. One participant had requested health materials on asthma written in English, so that she could improve her understanding: *'a bit of knowledge about why it's happening'* and how to manage the condition (female, 70, Indian Gujarati, asthma). One of the advantages cited about health information in leaflet form was the ability to keep it to refer back to if needed: *'I think leaflets are brilliant cos if you pick up a leaflet and you've got it at home, sometimes you want to go back to something, you have that in front of you'* (female, 41, Pakistani, borderline diabetes and asthma); *'leaflet is better; take home and read'* (female, 69, Indian/Kenyan, diabetes); *'with a leaflet I can read it again and again'* (female, 61, Pakistani, diabetes). Leaflets were seen as being more up-to-date and reliable than websites. For some, leaflets really did make a difference to their understanding and management of their condition. One diabetes patient changed her diet and started exercising after reading the health advice in leaflets:

I've been reading leaflets. At the time, I was feeling very angry with myself and angry with the doctor too, cos if I'd known then early on I could have done something to prevent it (female, 61, Pakistani, diabetes).

As noted above, for several participants, receiving health information via written material did not work (for reasons pertaining to literacy and visual impairment). Offering written material in more accessible formats - in large print, for instance - may be one way of addressing this issue. An additional approach may be to present health information via a different medium, beyond the written word. In line with the evidence review, some participants acknowledged the value of community radio as a way of receiving information about diabetes. Others suggested using videos:

11 o'clock, I like to listen then and they bring this dietician and this and that and they talk and people ring to ask them what to do (female, 69, Indian/Kenyan, diabetes).

Sometimes I do listen to the radio cos they teach you really good things. There was this woman who was an Indian Muslim and she used to always give advice about 'eat this' and 'this is the right food for diabetes'. She used to give very good information but she isn't around anymore (female, Pakistani, diabetes).

I know how important it is and how much awareness comes out of the media side of it so that's one of the positive things that really helps with illnesses (female, 41, Pakistani, borderline diabetes and asthma).

I think audio video helps as well cos when you see something you remember more (female, 64, Pakistani, asthma).

Yes, videos [...] I think that's more effective. The leaflets, sometimes people don't bother reading it all (male, over 70, Pakistani, diabetes).

Face-to-face contact, including the Juggle Diabetes Service, along with outreach workers, and speaking with others who are living with that condition, was a valued method of learning about the management of their long-term condition for many participants. Being able to speak to a health expert face-to-face allowed patients to ask questions and seek clarification. It was felt that an outreach worker could offer more personalised and tailored advice, especially if they were part of that community ('a cultural ambassador'):

Then things can be explained properly. If you look at a leaflet you're not going to be particularly bothered by the information in it, you might think let's not bother [...] But the way you're talking to me, that's better, a person's body language tells you things regardless of the language, whether it's English or Urdu, people can understand through gestures (female, 38, Pakistani, diabetes).

How they tell me verbally is best (female, 60, Pakistani, diabetes).

If someone tells you they're normally more important, you don't read a leaflet. If my daughter talks to the outreach worker about her own experience she'll get a response that's in tune with her experience; whereas a leaflet is more generic, it applies to everyone (female, 35, Pakistani - on behalf of daughter, 14, asthma).

I: How would you like to receive information? What would work best for you?

R: It would be better if someone explained it to me (male, 64, Pakistani, diabetes and asthma).

If you talk about it I think it sticks in better, but as soon as you get in you put the leaflets down and that's it then (female, 80, African Caribbean, diabetes).

It's best to hear it from the person who's having to live with that condition [...] cos I'm suffering with it, I'm able to empathise and sympathise with people about how they are [...] it has more impact and it's always nice when you can identify with someone from your own culture (female, 63, African Caribbean, diabetes).

The value of outreach work with specific communities in places they frequent was also recognised as an effective strategy by stakeholders, for reaching those communities traditionally difficult-to-reach. It was suggested, that ideally, the outreach workers should hold the cultural awareness and knowledge of the beliefs of the communities they go into, and, fundamentally, possess the necessary language skills to communicate with those for whom English is not a first language.

Whilst a small number of participants expressed a need for receiving appropriate information about their condition in their main languages, including in Urdu, Polish and Hindi, one Polish participant felt that she had no need for translated information due to being able to access this herself: *'I can search for the information I need on the internet'* (female, 58, Polish, COPD). Her approach to researching and understanding her condition, based on a fairly good level of IT literacy, was not a realistic expectation of most of the other participants for whom English was a second language.

5.3. Participant feedback on the sample diabetes leaflet

During the interview, participants were shown a sample health pamphlet for diabetes (see Appendix 2), and asked for their feedback on: how effective it was at communicating health information; how well they understood it; and how it might be improved. On the whole, participants were positive about the leaflet: its layout, design and content. In relation to the design and layout, participants liked its simplicity and its use of graphics and visuals. Many participants, especially those whose first language was not English and those with poor literacy skills, gleaned an understanding of the health messages being communicated through the images:

It's quite important having something because people capture images in different ways. Some people would look at things and it would capture their imagination and attention (female, 53, African, asthma).

Picture is better cos is self-explanatory (male, over 70, Pakistani, diabetes).

Many participants found the inclusion of phone numbers for specialist diabetes services within their communities useful. As participants said *'if you're not sure you can just ring that number and ask them'* (female, 37, Pakistani, diabetes); and *'it's well laid-out; it gives you numbers you can get help from; it tells you what you need to do from your eating to caring for yourself as a whole'* (female, 55, Black British, diabetes and asthma). To make the leaflet more accessible for younger diabetes patients, one participant suggested including links to websites about diabetes management and services in addition to phone numbers. This participant would have preferred to find out more information online rather than over the telephone, and suggested an online version of the leaflet to accommodate for younger generations who tend to search for information using their mobile phones:

Websites or maybe an app or something would be good. Now a lot of people are on their phones all the time, so instead of leaflets I think it's better for them to make apps and probably save money as well by less papers [...] I think people are more likely, when they're bored, to go on the app (female, 30, Pakistani, diabetes and asthma).

Due to literacy and language barriers, several participants struggled to read and understand the leaflet as it was printed in English: *'It's difficult cos it's in English'* (female, 42, Pakistani, diabetes); *'To be honest I struggle to read English, I'm quite weak at it, I can read a little bit and also I haven't got my glasses'* (male, 64, Pakistani, diabetes and asthma); *'I can recognise some of the words and know the meaning but not quite sure what it's all about other than it's for diabetes'* (female, 46, Polish, asthma). As touched upon in Section 2.2, participants with poor literacy skills asked family members to translate the leaflet: *'for something like this, she'd probably ask her children to translate. She can read it but for understanding she'd get them to explain it'* (female, 63, Bangladeshi, diabetes); *'normally everything's done for her through her husband and her children'* (female, 66, Bangladeshi, diabetes). As a way of addressing language barriers, it was felt that the leaflet should be available in a range of languages, and that the English language version should specify that: *'I've not seen anything saying it's available in other languages'* (male, 40s, African, diabetes); *'in my case it would need to be translated into Polish'* (female, 46, Polish, asthma). As well as reaching a range of BAME groups through the translation of the leaflet, it may reach a wider audience by being made available in community settings: *'making sure these are also available in local mosques, local cultural youth clubs and centres [...] I think people would find it more accessible'* (male, 40s, African, diabetes).

Religious and cultural barriers

Key Findings

- The research found that the role of religion in participants' day-to-day lives varied; from playing no role at all to a very significant one.
- Vast amounts of 'faith' and 'trust' were placed in god as providing support above and beyond assistance of any other kind. A sense of hope ran through many accounts, which underlined that the ultimate trust lay in god.
- Members of some BAME communities remain poorly educated in religious principles related to their health, suggesting that community leaders could play an educative role in their communities using religion to influence change.
- There was some recognition of various cultural factors and discussion about how they influenced health. Members of a range of BAME communities talked about their diets; the richness of food; and the cultural practice of adding oil, salt, and sugar to food.
- The cultural practice of living with extended family emerged as an interesting finding due to its implications for managing diabetes.

6.1. Introduction

When seeking causes for their condition, religious explanations such as 'god's will' and 'fate' were mentioned by Hindu participants involved in a study by Kohli and Dalal (1998), which was reviewed for this research. They looked beyond medical explanations when trying to make sense of their health conditions, and conveyed an acceptance of their own suffering and that of others. Knifton's (2012) research with three BAME communities cited their religious beliefs as a barrier to seeking treatment for mental health because they also viewed their condition as coming from the will of god, and therefore medicine was not seen as offering a cure. Similarly, according to a study by Chowbey *et al.* (2008) people from the Pakistani community with eating disorders delayed seeking medical help due to their belief in god's will and in religious spiritual healers as holding the cure.

The evidence review highlighted cultural barriers to the uptake of health services including: a preference amongst some communities to use herbal remedies (Wilson *et al.* (2012); and the concealment of ill-health (Salway *et al.*, 2007). The latter barrier explored by Salway *et al.* (2007) revealed evidence of the 'concealment' of ill-health across a number of different ethnic groups. BAME participants related the concealment of their health conditions to expected norms for their ethnic community.

For example, Pakistani and Bangladeshi women's concealment of their condition was associated with expected norms of women to suffer with patience and in silence, with the perception that through this they gained strength and moral position.

The studies stressed that health professionals should acknowledge the role of culture and religious beliefs when communicating with patients in order to engage better with different ethnic groups and to encourage the uptake of services. Increased awareness and knowledge of the different beliefs, myths, practices and social norms on health and ill-health should also encourage adherence to treatment routines and medical advice (Kohli and Dalal, 1988). Fundamentally, by becoming more knowledgeable, on the specific needs and preferences of BAME communities, practitioners move towards achieving a situation of shared understanding and trust, both of which are necessary for encouraging the uptake of services, and, in some cases, respectfully challenging beliefs and norms.

6.2. Influence of religious beliefs on views of health

Barriers

The data revealed that the role of religion in participants' day-to-day lives varied; from playing no role at all to a very significant one. Indeed, several participants reported that religion did not play any role in their daily lives at all. While a number of participants affirmed their Christian beliefs, none of them claimed that Christianity played such a significant role that it pervaded their day-to-day lives in any way. A few of them went to church weekly, but not always regularly:

I: What about religion, does it play a role in your day-to-day life?

R: Not substantively, I am a Christian but it doesn't restrict me majorly if that makes sense (female, 48, Black African Caribbean, asthma).

I: Does religion play a role in your day to day life?

R: It is to some extent, not like it makes a huge role in my life. I'm Catholic and I attend church but not on a regular basis (female, 58, Polish, COPD).

I: Are you religious?

R: I'm not a mad religious person, I do go to church occasionally, but I'm not that big on religion (female, 61, Black British, diabetes).

Muslim participants, on the other hand, recognised religion as playing a significant role in their daily lives: praying five times a day; fasting during the month of Ramadan; with some of them going to the mosque. Such commitment to the regular practice of religious beliefs signalled potential implications for the uptake of long-term conditions services. In a sense, Islam was conveyed as prescribing a way of life - for example, requiring five prayers to be observed at specific times each day, with followers showing considerable dedication:

I: Does religion play a role in your day-to-day life?

R1: Yes it does. She does prayers.

R2: I five time pray [each day] and read the Quran every time (female, 63, Bangladeshi, diabetes).

I: What about, you're Muslim, does religion play a role in your daily life?

R: Religion is very important to me; I practice as much as I can (male, 58, Pakistani, asthma).

I: How important is religion to your day-to-day life?

R: It's very important, it's my whole life.

I: So you do your prayers and fast?

R: Yes of course (female, 42, Pakistani, diabetes).

I: Do you pray five times a day?

R: I do my prayers five times a day. Everything is my faith, I haven't made friends, I spend most of my life dedicated to my faith (female, 38, Pakistani, diabetes).

Interviews revealed that, for many participants, religious beliefs played an influential role on their views of health. Vast amounts of 'faith' and 'trust' were placed in god as providing support above and beyond assistance of any other kind. A sense of hope ran through many accounts, which underlined that the ultimate trust lay in god:

I trust god will help me to look after my health, I have faith in god (female, 73, Chinese, diabetes).

I: Does her religion make her accept her diabetes more?

R: God will look after her (female, 81, Chinese, diabetes).

I: How does it [religion] influence your health for example?

R: I don't think it does; if anything it's positive cos we're praying to god all the time and there's no-one other than god that can actually help you, obviously there's medicines and doctors, but underlying things it is god so we just pray and it [religion] plays a really positive role (female, 26, ethnicity not stated, diabetes).

Despite the unwavering religious conviction expressed by a large number of participants, the teachings of religion (in this case Islam) on maintaining good health were emphasised only in one account:

If we were to follow our religious views [meaning teachings] many of us wouldn't even be diabetic cos we believe our body is god's, if we harm our body, if we feed it junk food and make ourselves diabetic and can't get up and do stuff, so it's diet, exercise, stay slim, there's a lot into it, they've said fasting, have one meal a day, cut your food and stuff, eat less, don't over-indulge in your food cos it makes you lazy and you can't be active to do your religious duties (female, 30, Pakistani, diabetes and asthma).

Aside from this narrative, there were no references to, or, any demonstrable in-depth understanding of religious guidance on the importance of taking personal responsibility and ownership of one's health in terms of diet and exercise. The importance of this finding is in the indication that members of some BAME communities remain poorly educated in religious principles related to their health, suggesting a potential role for asset-based approaches to healthcare whereby key community leaders play an educative role in their communities using religion to influence change. In the stakeholder interviews, religious beliefs were recognised by most health professionals as being integral to the identities of some people. Key figures such as community leaders, priests, and imams were perceived to have a significant influence on their local community members – not only on religious matters, but on most aspects of their lives, including health.

A belief in religious (Islamic) practices as helping to manage another participant's diabetes highlighted the possibility of some religious education as having an adverse effect on the uptake of long-term conditions services. Although, in this case, a reliance on a combination of alternative religious remedies and conventional medicine was cited:

I: Are there any other things you've learnt about through your religion through which your condition could be improved?

R: Yes lots, there's one surah [prayer] that we read and blow on the water and drink it and if we have aches and pains there's a prayer we can read, believe me in our religion if you've got diabetes you can read this prayer and we read that and I think it's cos of that prayer that my diabetes is under control... If it was about dependency just on medication we'd have passed away by now (female, Pakistani, diabetes).

Enabling factors

While several participants expressed dedication to their religion, and the belief that their health condition was prescribed by god who would support them through it, they also acknowledged that they too would have to be proactive in managing their condition themselves:

I: Some people might think that if god looks after them they might not change anything cos god will take care of them?

R: Only god won't do anything, you have to do it, you too have to take part in it, if you won't do it what will he do? He can only give us the understanding to look after ourselves (female, 67, Pakistani, diabetes).

I: You just told me that illnesses come from god, so if the diabetes is from god, do you think that that's it now, I can't do anything about it? Or do you think I've got diabetes but there's something I can do about managing it?

R: Yeah of course I can do something about it, if I control certain things (female, 42, Pakistani, diabetes).

When questioned on long-term conditions and fate, one Muslim participant firmly rejected the stance that religion might allow individuals to absolve personal responsibility. She declared, '*of course you should do something [about your condition], illness is due to our own mistakes because we eat bad food, that's why we get ill*' (female, Pakistani, diabetes). A Sikh participant also challenged the concept of 'fate'. Although religious, he felt that ill-health should not be viewed as given by god and, '*if you have a bad disease you need medication, you need NHS; that is more important*' (male, 74, Indian British, asthma). Moreover, other interviews

revealed that religious beliefs should not be perceived as imposing limitations and that both religion and conventional medicine work hand-in-hand:

Religion doesn't say "stop doing this". If you need it you have to take it, so no religion problem (female, 69, Indian/Kenyan, diabetes).

I: Yeah you have god but you still have to take the medicine (female, 68, British Chinese, diabetes).

I: How do your religious beliefs influence your views on your health?

R: A lot, I'm a dedicated Christian and for me, I have a very strong belief and I will pray about my health and that's why I have this belief that I can be healed of my diabetes. I wouldn't just come off the medication, I would prefer to go and see my nurse (female, 63, African Caribbean, diabetes).

Evidently, the value of medical support is acknowledged by participants; however, it is worth noting that religious conviction plays a vital role in providing psychological support, peace of mind, and optimism when trying to manage a long-term health condition. Both sources of support – medical and religious – have their own distinct place and there is little crossover between the two from a practitioner angle. Yet, the importance of both for managing diabetes and respiratory conditions runs through the narratives of several participants:

I: How do your religious beliefs influence your views on your health?

R: It's not that I won't accept some treatment, or I would accept some treatment, it's more moral support when I can talk to and share my problems with Santa Maria and then it makes me feel better (female, 55, Polish, respiratory condition).

6.3. Influence of cultural practices on health

Barriers

Overall, there was some recognition of various cultural factors and discussion about how they influenced health. Members of a range of BAME communities talked about their diets; the richness of food; and the cultural practice of adding oil, salt, and sugar to food:

I: How do his cultural practices influence his health – for example his diet, lifestyle or commitments to others?

R: It's correct because our culture we have to put some oil or more sugar (male, 72, Chinese, diabetes).

What we eat and what you eat is a huge difference, we have oil and we're cooking curries in oil and Asians add a lot of salt. I don't but other people do (female, 30, Pakistani, diabetes).

I didn't know this palm oil, if you take it too much it can affect you (female, African, asthma).

As some participants learnt about the adverse effects on their health of having high salt, fat and sugar content in their diets attempts were made to reduce these foods:

But I learn it now, I try to keep on less sugar and less oil and less salt (male, 81, Chinese, diabetes).

I'm very conscious about my diet and I didn't eat a lot of fat things and I didn't eat a lot of sugars and salt (female, 78, Chinese, respiratory condition).

As a result of the changes some participants made to their diets (i.e. cutting out some of the aforementioned ingredients) they found themselves having to cook separately for family members, which clearly took more time. Only in one interview family members were reported as being supportive by eating the same food. In another account the participant found it difficult to resist foods that she had to control in her diet when seeing family members: *'sometimes my husband and my sister-in-law eat a lot of junk so if it's there I'll be like I'll have a bit of that'* (female, 26, South Asian/White, diabetes). In another example, the changes in a participant's diet made it difficult for the whole family to observe their usual cultural practice of eating from the same plate:

It is a bit difficult depending on your family otherwise you have to make two curries but I add less salt, less oil (female, 30, Pakistani, diabetes).

I: So you have to cook two different meals?

R: Yeah then I eat different, less salt, less oil.

I: Does that take up a lot of time to do two separate meals?

R: Yeah (female, 53, Pakistani, diabetes).

It has changed the diet for the family, there are things that they can eat and I can't, so culturally we tend to eat from the same plate and share quite a lot of food but it has changed to some extent, so it does impact on their lifestyle apart from just my diet (male, 40s, African, diabetes).

The cultural practice of living with extended family emerged as an interesting finding due to its implications for managing diabetes. In this case, the extended family comprised of different generations living together. Hence, people of various ages with different food preferences and health situations ate together. They ate the same food, with the diabetic member (participant) of the family having a smaller portion. However, the participant's daughter pointed out that their eating times dictated hers, which were not suitable for her as a diabetic:

But we eat as a family and as a diabetic she should be eating less and often but she tends to go with the majority, so we eat at irregular times but she wants to join in with the family where we tell her you have to eat at other times too. If she lived on her own she would have her own timetable (female, 63, Bangladeshi, diabetes).

While acknowledging that Asian food can be unhealthy, a few participants chose to reduce their portion size instead of eliminating it entirely from their diets. One commented, *'they are too sweet, but I take like that, but if I take like that I don't eat anything more, like two, three chapatti, I eat only one chapatti a day'* (female, 71, Pakistani, diabetes). Another participant reiterated, *'it's just about eating in proportion'* (female, 26, White/Pakistani, diabetes). A Gambian participant explained

that he struggled to cut down on his intake of rice – a staple food – and found it difficult to work out the correct portion size (male, 40s, African, diabetes).

A couple of accounts emphasised a lack of awareness around correct eating times and revealed how cultural practices such as irregular and late routines potentially impacted on the management of long-term conditions:

I used to be a chef and worked very late and had to eat a lot of food after but the healthy people told me I'm not supposed to eat during the night-time or midnight (male, 72, Chinese, diabetes).

We have this thing of staying up late, not eating at the right times, we eat with family a lot and go out at late times and I don't think they [other family members] do get that, but that actually can affect your asthma (female, 28, Bangladeshi, asthma).

A recurring theme related to the challenges of eating healthily during special occasions when families and/or friends got together. Several participants expressed the difficulty of exercising a degree of control on such occasions:

Then you have to eat the food (female, 61, Pakistani, diabetes).

It might be that I go to a wedding and I eat the wrong foods and then sometimes I can feel unwell (male, 64, Pakistani, diabetes and asthma).

Another participant conveyed the pressure to attend cultural events, such as weddings, where rich and oily foods were eaten, but where attendance was necessary *'to maintain good relationships with people. Those things take its toll'* (male, Pakistani, diabetes). In another example, an Indian participant described the pressure he encountered from people when he went to the temple where Indian sweets were distributed routinely:

I'm controlling my food, but people still keep forcing 'have another one' (male, 74, Indian British, asthma).

Culturally, eating certain foods was believed to have remedial properties. Some of this seemed harmless – for example, replacing wheat flour with corn flour. But other practice indicated potentially more damaging repercussions – such as ignoring medical advice; taking alternative remedies; and reducing the amount of medication prescribed without consulting the doctor first. The empirical evidence suggested that cultural alternatives to medicine were being used for managing health conditions without seeking assistance from health professionals:

We eat chapatti made from corn flour, that's good for diabetes...It's advisable to eat adjuar dates and if you eat it in the morning it's good for diabetes. These tablets, I only eat my tablet that my GP gave me once a day cos the other time I'm careful and watch what I eat, adjuar dates, if you eat those they're very good for you (female, 38, Pakistani, diabetes).

The participant revealed that both her brothers had diabetes too. The younger brother, like her, *'doesn't eat tablets either, he has adjuar dates, he has his own cultural treatments'* (female, 38, Pakistani, diabetes). This comment indicated that cultural practices involving replacing medication with alternative foods were shared and possibly widespread, especially in extended families and within tight-knit communities, thus having potential implications for the uptake of long-term conditions services.

Cultural practices focused on obligations to others were often undertaken at the cost of individuals' own interests and wellbeing. This could involve visiting family members (including extended family), close friends or members of the community who were very ill, or visiting those preparing to go on pilgrimage, and then visiting again upon their return. Culturally, these visits have become obligations, and according to one participant, *'these are the big problems in our community'* (female, Pakistani, diabetes).

Enabling factors

While the use of herbal and natural remedies, and their perceived benefits, was discussed in a few interviews, there was no suggestion of using these as a complete replacement to conventional medicine and health services. Indeed, the importance of conventional medicine was recognised:

I: In terms of her belief in Chinese herbal medication, does she put that at the forefront? If she has a choice to use herbal medication or to go and see her GP or to use health services, which one would you choose?

R: she would go for the doctor first cos the Chinese medicine is very expensive, That's £30 each time.

I: Which one does she think is most effective?

R: For emergency GP is the best (female, 64, British Chinese, respiratory condition).

I also believe in herbal medicine and I travel to the Caribbean a great deal so I've developed my own way of drinking certain natural remedies to help my diabetes (female, 63, African Caribbean, diabetes).

The expectations for patients to change their diets emerged as an important area in our research. Evidence indicated that the proposed changes were sometimes too drastic and not always in line with cultural diets. Often, participants continued to eat the same foods, attempting to reduce the amount of salt, fat, sugar, or their portion sizes:

The hardest thing has been, Bengalis, the diet is heavily based on rice, rice is the main portion and then you add on the meat, fish and vegetables but everything's fried in oil so having changed all that doesn't leave very much for them to eat, hence why I think she couldn't stick to a diet scheme that's been provided by the NHS cos it doesn't follow her lifestyle (female, 66, Bangladeshi, diabetes).

Our findings suggest that practitioners and service providers that are detached from the realities and cultural observances of their patients might deter their engagement with services. The aforementioned experiences call for the delivery of health services in a way that reflect cultural awareness and understanding appropriate to the communities served.

Sources of support

Key Findings

- The doctor was perceived by a large number of participants as being best placed to provide assistance to them with regards to their long-term health condition.
- The Diabetes Specialist Nurse was recognised as playing a more significant role in the management of diabetes. Patients valued nurses giving them time and listening to them, providing emotional support in the process in relation to their condition.
- Resources within communities, such as local community organisations, were viewed as providing a valuable source of support, particularly as the shared understanding of those accessing such places was based on similar cultural norms and values, creating familiarity and trust.
- Family members played a significant role in providing emotional and predominantly practical help to their relatives with diabetes and/or a respiratory condition – including practical help with household chores, lifts to appointments, interpretation and translation.
- There was a general lack of awareness about self-help groups, with only a few participants having accessed them. Although most participants had not attended a self-help group, when the principles were explained to them, the majority agreed with the idea and expressed interest when asked if they would attend in the future.

7.1. Introduction

The review of literature highlighted a number of key findings in relation to sources of support for patients, including: where doctor-patient communication was poor, this resulted in poor management of health conditions (Raleigh, 1997); patient adherence to practitioner recommendations and advice was dependent on practitioner communication skills and cultural sensitivity (Basáñez *et al.*, 2013); and a lack of trust in health professionals by some BAME people was raised as a barrier to uptake of services (Knifton, 2012; Gerrish, Ismail and Naisby, 2010). Perceptions of doctors

as being 'all-knowing' and best placed to meet health needs compared to nurses who were seen in assistive roles signalled implications for the underuse of specific services in another study (Boman *et al.*, 2015).

Family structures also have a bearing on the use of health services according to Chowbey *et al.* (2008), who stressed that service providers should gain some insight into the diverse BAME family structures and the obligations and inter-dependency that exist within them to understand what might encourage or deter the uptake of services. The role of family members in providing support and encouragement for adherence to healthy behaviours was acknowledged (Lin *et al.*, 2007) as well as how strong social networks assist in relation to service uptake – providing help with interpreting, for instance (Pang *et al.*, 2003).

Self-help groups and local community organisations were recognised as providing opportunities for sharing knowledge and experiences on health and assisting people from BAME backgrounds to gain better understanding of their health conditions and how to manage them (Raleigh, 1997).

7.2. Which health professionals are best placed to help

Barriers

The doctor was perceived by a large number of participants as being best placed to provide assistance to them with regards to their long-term health condition. For most, the doctor held a position of authority based on having the most knowledge about their health; hence patients believed in and acted upon their doctors' advice. A number of comments sum up the position of the doctor in participants' estimations:

I: Is it the doctor in your view that's best placed to help you with your diabetes?

R: Yes, whatever the doctor says, if the doctor asks you to take the medicine you take it (female, 68, British Chinese, diabetes).

The doctor always has the right solutions (female, 60, Pakistani, diabetes).

I: So you think your doctor is in the best position?

R: Yes he's in the position to explain, he has the authority (male, 74, Indian British, asthma).

Certainly, doctors were perceived as having more knowledge and training on diabetes and asthma than other health practitioners, including the specialist nurses. In one participant's view, both doctors and nurses were qualified and trained professionals, whereas Juggle staff were trained but not medically qualified, therefore her faith rested in the doctor. Similar to the findings of our literature review, utmost faith and trust in the doctor was a major narrative in numerous accounts:

I: Do you prefer seeing your GP or the nurse?

R: I don't mind, when I need the nebuliser they can both help me, the doctor knows more than the nurse.....cos he checks my lungs and everything

I: So you feel the doctor has more specialist knowledge on asthma than the nurse?

R: Yes (female, 49, Pakistani, asthma).

He know what he's doing, nurse has not that much knowledge (male, 74, Indian British, asthma).

Obviously the doctor will decide what is better for you cos they've done that training (female, 30, Pakistani, diabetes and asthma).

If I had to ask something I would be asking the doctor (female, Pakistani, diabetes).

The elevated status of the doctor compared to other healthcare specialists was problematised by several respondents in the stakeholder interviews. Certain advice and services, where the doctor's input was absent, were felt to be less likely to be taken up.

Many participants also expressed trust in their nurse – in comments such as, *'I totally believe my GP and my professional nurse cos they manage my health. I will believe them, I trust them'* (female, 73, Chinese, diabetes), and, *'trust in nurse and doctor, so act upon their advice'* (female, 71, Pakistani, diabetes).

In a few interviews, the Diabetes Specialist Nurse was recognised as playing a more significant role in the management of diabetes and being *'specialised in the diabetic field'* (female, 26, White/Pakistani, diabetes). A preference to see the nurse specifically for diabetes support was expressed. For instance, a few participants remarked: *'she'll go through more stuff with you'* (female, 30, Pakistani, diabetes); *'she's quite thorough so I'm quite happy to go to the nurse'* (male, 8, Bangladeshi, asthma); *'I think I go to my nurse more often, cos she knows everything about it, I had her from the start and she knows everything'* (female, 14, Polish, asthma); *'the nurse has told me everything, the GP is just responsible for my overall illnesses, he didn't tell me about my diabetes'* (female, 42, Pakistani, diabetes). Only in one case, the nurse was viewed negatively for being overbearing when giving advice on diabetes (female, 61, Pakistani, diabetes).

Indeed, the GP was identified as being responsible for general health, with *'an overall view'* of an individual's health (female, 41, Pakistani, borderline diabetes and asthma):

I: Who do you trust the most in terms of helping you manage your health condition?

R: I would say my diabetic nurse cos that's what's her speciality, with the doctor they look at all aspects, but with the diabetic nurse she sees diabetic people day in, day out... I haven't really seen my GP as much for my diabetes than I see my nurse. It's good cos I've got the one nurse, she doesn't keep changing, she knows my history, she knows me, and it's not that I see a different face every time I go and I have to start explaining from scratch cos that would get annoying after a while (female, 30, Pakistani, diabetes and asthma).

The last point stressing the importance of continuity in care by the same health professional resonated with other participants too. However, they were not as fortunate to see the same nurse over a sustained period of time necessary to create familiarity and rapport; a high turnover of staff led to frustration in a few cases:

Special nurse she I think is two years there and then she left and then another specialist nurse (female, 53, Pakistani, diabetes).

If you're going to see a stranger every time it's no good cos they don't know what's wrong (female, 80, African Caribbean, diabetes).

I don't know, just lately we've got different, every time you go there's a different nurse, but before we had one nurse who was always there and you were seeing the same person so it did help, but if you go and see someone who doesn't know you you've got to start again, you've got a limited amount of time to explain about yourself, but it is good to see somebody regular (female, 55, Black British, diabetes and asthma).

Enabling factors

The approachability and kindness of specialist nurses was repeated in several accounts - they were described as being accessible and attentive:

I think the nurse is more approachable and more gentler with it and she seemed to know what she was doing so I'm ok with the nurse (mother, speaking about son, 10, African Caribbean, asthma).

I: So there's a lot of trust between you and the diabetes.....

R: Yes with my diabetes nurse, cos you find her always welcoming and supportive and when you talk to her she's always willing to listen and will also give you advice and she would always ask you to call her if you need anything (male, 40s, African, diabetes).

I trust them wholeheartedly cos I know some days if I'm feeling a little bit low with the sugar I know I can just pick the phone up and ask to go and see the nurse, so it is nice to have that element of trust that I know there's someone at the end of the phone that I can just call and have a chat with (female, 63, African Caribbean, diabetes).

Patients valued nurses giving them time and listening to them, providing emotional support in the process in relation to their condition; something which GPs were recognised as having little time to do. One example underlines some of the reasons for preferring to see the nurse over the GP:

I: So you see your GP and your nurse... which health professional do you feel out of the two is best-placed to assist you with your diabetes?

R: Probably the nurse cos she's got a bit more time to talk with me, there have been occasions when my diabetes was a little bit too high and she would have the time to talk with me to find out what's gone on and give the option, come back and see me in four weeks, that has happened, with the GP they really don't have the time for that, so I'm quite happy with the support I get from my nurse (female, 63, African Caribbean, diabetes).

As language skills are so closely aligned with acquiring knowledge, undoubtedly the practitioners closer to meeting the overall needs of patients were those with the necessary skills to communicate effectively with them. This was reflected in the accounts of a number of participants who gave language as a reason for the doctor being best-placed to assist with their health condition:

I: Which health professional do you feel is best-placed to assist you with your diabetes?

R: Doctor because speak Chinese (female, 81, Chinese, diabetes).

My doctor speaks Urdu. So in my opinion, that is very good. The lady at the course (Juggle) was helpful too (male, Pakistani, diabetes).

Resources within communities, such as local community organisations, were viewed as providing a valuable source of support, particularly as the shared understanding of those accessing such places was based on similar cultural norms and values, creating familiarity and trust. This view was emphasised by a participant who commented, *'having your own community is the best thing sometimes'* (female, African, asthma). These organisations were described as being accessible and open to the local communities for welfare support, advocacy, training and education. A member of staff from the Nottingham Chinese Welfare Association, interpreting on behalf of a research participant, explained, *'he always come here I think, nearly every week'* (male, 72, Chinese, diabetes). In another example, where an individual had limited support, she was able to rely on the Asian Women's Project. She reported, *'there's just my daughter [for support] or I can come to the centre'* (female, 60, Pakistani, diabetes).

A Bangladeshi participant presented an insightful example into the benefits derived from taking health services into local communities; for both the service users and the providers. She highlighted that, in some communities, leaving the home was difficult and presented *'a problem in some cultures'*. A home visit from the diabetes nurse meant the whole family could be educated collectively. The home visit was reported as being *'really helpful, it was about 15/20 minutes'* (female, 28, Bangladeshi, asthma) and educated several members of the family at once so they were able to better support the participant.

7.3. Family and friends

Barriers

Our interviews revealed that family members played a significant role in providing emotional and predominantly practical help to their relatives with diabetes and/or a respiratory condition, and this is discussed in-depth in the subsequent 'enabling factors' section.

However, in some cases, family members were not always able to offer much support due to their work commitments. One participant complained that his/her son was too tired to listen to his/her health problems and therefore unable to offer emotional support and another explained that his daughter was only able to fit in taking him to important hospital appointments, but could not assist with GP appointments:

I: Does she provide any other support?

R: No, she's very busy, she's working (male, 72, Chinese, diabetes).

They're all very busy (female, 38, Pakistani, diabetes).

In a small number of cases, participants reported receiving minimal support from family members mainly due to their lack of knowledge about their health condition:

They're a bit ignorant about it and it's not their fault cos they don't have the knowledge of it (female, 28, Bangladeshi, asthma).

I don't think they've got any idea with this thing, I've got my children coming to see me, how I'm feeling and this and that but they don't have knowledge about this thing (female, 69, Indian/Kenyan, diabetes).

Evidently, some participants' children were taking time off work or school to attend appointments to interpret for them, or they would arrange interpreters for their parent(s) in a few cases. This was reiterated by one account in particular: *'Her children call for her. It's half and half, sometimes her son goes with her, sometimes the interpreter'* (female, 68, British Chinese, diabetes).

However, it also emerged that many participants were not seeking medical help due to their concern about burdening their children with requests for help with interpretation and lifts to appointments:

Sometimes I need to ask my children to make doctor's appointment for me, because my children need to go to work and I don't want to trouble them (female, 78, Chinese, respiratory condition).

A couple of interviews highlighted that participants put a family member's health condition before their own, suggesting that these commitments might affect their time to take up services for their own wellbeing:

I: Do your family and friends help you in managing both conditions?

R: No cos my dad is diabetic so I'm giving him more support than myself and asthma, cos mine is well controlled compared to my mother, my daughter, my brother, with them the slightest dust allergy and it's like they're on death's door, theirs is really bad (female, 41, Pakistani, borderline diabetes and asthma).

I: Do your family and friends help you manage your condition?

R: No, it's me always running after them (female, 41, Pakistani, diabetes).

Enabling factors

Evidence revealed that family members played a significant role in many participants' lives, helping them to manage their long-term condition. Advice was received from near and far, including from family living abroad. Children, nephews, nieces, spouses were all mentioned as providing a range of support, including practical help with household chores, lifts to appointments, interpretation and translation. They were also cited as offering advice, *'they say "eat this, don't eat this", so I can understand'* (female, 60, Pakistani, diabetes). In some instances, family members proactively sought healthy dietary options; and in others, they provided emotional support:

Well my kids know and they always try, they keep asking me about my diet, my daughter does research into what I should eat, if she finds that something's good for me she buys it for me, she does help, my son does, my children do help (female, 61, Pakistani, diabetes).

Moral support or if I need something, they'll get my prescription if I can't go or something like that (female, 64, Pakistani, asthma).

In another example, the participant's daughter acknowledged that the family's routine for meals did not suit that of their diabetic mother and inadvertently isolated her at meal times. She considered the changes that they could make collectively to support her, whilst benefitting the family as a whole:

We should change with her rather her change with us, cos eating small and often benefits everyone so I think we as a family should help her by joining in as well, she doesn't like to eat alone (female, 63, Bangladeshi, diabetes).

In several cases, where family support was unavailable, friends played a role in accompanying individuals to appointments, translating health materials and correspondence, and interpreting on their behalf:

I: Who helps when you go to hospital?

R: Friends or if not she'll ask someone else.

I: So it's friends who read the letters?

R: Yes (female, 81, Chinese, diabetes).

Those (few) participants lacking support from family and friends were isolated – exacerbated by language barriers – and managing themselves with some help from local community organisations.

The importance of involving family members and carers in supporting individuals to manage their condition was acknowledged by health professionals in the interviews with stakeholders. It was felt that involving the family more in the patient's ongoing care would help them to manage their long-term condition, especially in terms of implementing lifestyle and dietary changes at home.

7.4. Self-help groups

Barriers

There was a general lack of awareness about self-help groups, with only a few participants having accessed them. Although most participants had not attended a self-help group, when the principles were explained to them, the majority agreed with the idea and expressed interest when asked if they would attend in the future:

If there is a self-help group I would like to go (male, 81, Chinese, diabetes).

The times and locations of such groups were stressed by a number of participants as influencing whether they could attend or not – for instance, one participant commented, *'it would depend on the time they meet, but it's something I would consider'* (female, 48, Black African Caribbean, asthma). In another case, having a long-term condition was described as an isolating experience that could lead to depression; self-help groups were identified as a way of easing loneliness:

I: So you feel like someone at the end of the phone?

R: Yeah or just somebody to talk to or meet up with or go to a group, but you don't want to go to a group that's too far away (female, 61, African Caribbean, diabetes).

Accessibility and proximity was emphasised in a number of narratives, for example - *'I think it would be nice if there were little groups in your area that you could pop into and talk about food and how you're getting on'* (female, 61, Black Caribbean, diabetes).

Commitments to others were cited as barriers too, illustrated by the examples of having *'to look after the grandchildren'* (female, 73, Chinese, diabetes) and *'haven't got the time to go'* (female, 69, Indian/Kenyan, diabetes). Reliance on family members for lifts was given as a barrier by one participant who had already accessed a self-help group but could no longer attend. This can be seen in the following account:

I: What role, if any, do self-help groups play in helping you to manage diabetes, have you ever been to a self-help group with maybe women only there talking about diabetes and sharing their experiences?

R: She's never been to any, no she's been twice or three times but then she stopped cos she had to rely on dad to take her early mornings and they're [Ibid: he's] not early morning people (female, 58, Polish, COPD).

The language barrier emerged again as presenting a significant concern for participants when considering engaging with a self-help group. Chinese participants, for instance, explained that they would prefer to attend a group delivered in their first language:

I: Would you like to?

R: She would like to but if it's only in the same language (female, 63, Chinese, diabetes and asthma).

If they were Cantonese speakers that would be better (female, 81, Chinese, diabetes).

Correspondingly, one participant conveyed fear about not fitting in due to her ethnicity and difference in cultural background:

I'm not aware of how I could access those support groups, or whether I would be comfortable to access that support group, I might walk in and be the only African-Caribbean, I would then walk away (female, 63, African Caribbean, diabetes).

Noteworthy is information gleaned from a few interviews which revealed that while participants had not accessed self-help groups, they received group support more informally from family members with diabetes, sharing an understanding about cultural issues associated with their health:

We discuss it together, our sugar might be too high or low... Often they say be careful or have this cos it's got low of that, eat chicken instead of other meats, those kind of conversations (male, 64, Pakistani, diabetes and asthma).

If we go out women who have diabetes sit together and ask what do you eat, how do you manage it, I tell them I go to the gym and I control what I eat (female, Pakistani, 60s diabetes).

Clearly, benefit was derived from such arrangements, but the validity of the health information shared could be questioned, particularly if it was based on cultural knowledge and norms.

Enabling factors

As highlighted earlier, a majority of participants expressed a keen interest in attending self-help groups, despite having no prior experience of them. In essence, there was an interest in hearing about other people's experiences of living with diabetes and/or respiratory conditions and a hope to learn from them:

I would very much like to involve in such a group cos I can listen other people's experiences and the way they deal with their health conditions so that would be very useful for me (female, 46, Polish, asthma).

So that I could receive more information and meet more people and get more information from them so they could offer me some solutions (female, 42, Pakistani, diabetes).

I: Would you go along to that if there was a common language and you talked about a common health condition?

R: Yes I would very much like that, to hear about how other people are managing that condition (female, 58, Polish, COPD).

Self-help groups, for some people, were seen as providing the opportunity to meet people and share feelings, as well as information, potentially helping to meet the emotional needs of individuals, which sometimes health professionals and family members had limited time to do:

I: If there was a self-help group other than the GP or something in the community, would you access that?

R: Yes if it's available, sometimes people need mental support as well, emotional support (female, African, asthma).

The tension at home would also be released... there isn't as much support within the family, within the family you just have to do your duty, cook the food, there's no attention (female, 38, Pakistani, diabetes).

Participants recognised that doctors had limited time to spend with patients, and saw self-help groups as supplementing other health support and filling this gap by providing space and adequate time to talk and listen to others:

I: So in terms of sources of support, who do you think is best placed from the health profession side of things?

R: I'd say friends or these groups you go to as well as support from at least a nurse should be good, cos I know the doctors are busy (female, 55, Black British, diabetes and asthma).

The views of those who were accessing self-help groups were also heard in this research. Interestingly, one participant reported how her self-help group collectively organised to fight for a particular cause, the result of which was positive:

We wanted to set it up for others cos I said I'm borderline, I need somebody to fight the corner of those people who are on borderline and that's how I got involved and managed to get Juggle available for people that are borderline. Self-help groups can be good and I know they're a success (female, 41, Pakistani, borderline diabetes and asthma).

The participant (above) also reiterated that in order for the groups to run successfully there was a need to reflect the language, cultural and dietary needs of the specific communities they were serving, and this view was echoed in another account.

All of the experiences of self-help groups were positive – participants were comfortable and confident expressing their feelings in mutually supportive environments knowing that others had the same condition:

I think they're very good, the people are very friendly and talk to you nicely and explain whatever you want them to (female, 37, Pakistani, diabetes).

A great deal was learnt about diabetes by all of those attending self-help groups. One participant felt it was beneficial to have a self-help group organiser who was well connected and informed about the health condition – *'half the things I'd never heard about. The chap that runs it seems to know quite a lot, knows all the people to get in touch with so it's quite good'* (female, 80, African Caribbean, diabetes). This participant gained most of her knowledge about diabetes through the support group.

The educational aspect of attending a self-help group was repeated in another account:

We meet once a month, it's a group of men and women go there and people come and give us a talk about diabetes and food you should and shouldn't eat and the numbers, if you go under 5 you can get hypo, I learnt all that from going (female, 61, Black British, diabetes)

The accessibility of this group was also emphasised, *'I walk to it, it's in the community'*. Another participant remarked that if she were aware of a support group running in her vicinity she would attend (female, 80, African Caribbean, asthma). Indeed, a number of participants emphasised that self-help groups were based in local communities making them accessible.

Socioeconomic status and discrimination

Key Findings

- Experience of discrimination was very uncommon but participants' financial situations often influenced the extent to which they could maintain a healthy lifestyle.
- The cost of travel was a barrier to attending health appointments, which sometimes resulted in participants missing appointments altogether if they could not afford the bus or taxi fare.
- Managing their diabetes through maintaining a healthy diet was sometimes difficult for participants as they perceived healthier food to be more expensive.
- In cases where participants were the main or secondary carer for a partner or relative, this often conflicted with the time they had available for attending health appointments, attending other services in the community, and maintaining a healthy lifestyle.

8.1. Introduction

Through the evidence review we identified that socioeconomic factors – such as financial pressures; insecure income; family and caring commitments; immigration issues - can impact on the uptake of long-term conditions services, self-management and the ability to keep health appointments. Individuals living on a low (sometimes insecure) income and juggling multiple pressures and obligations may struggle to make healthcare a top priority (Chowbey *et al.*, 2008). Discrimination (and patient perceptions of discrimination) also act as a barrier to care and a contributor to health disparities (Piette *et al.*, 2010; Peek *et al.*, 2011).

8.2. Finance

Barriers

While a participant's financial situation did not seem to have much bearing on medication purchase (as prescriptions were free for the majority of participants), it did often influence the extent to which participants could maintain a healthy lifestyle (exercise and purchase of healthy foods, for instance). Although treatment was free

for diabetes patients, there were often other hidden costs involved. For instance, one participant with diabetes was advised to purchase a blood sugar monitor but could not afford to buy the strips and needles for that particular model, *'I bought the machine and you only get 10 strips and 10 needles so once that's done, if you want it you have to keep buying it'* (female, 55, Black British, diabetes and asthma).

Exercise classes and gym membership were often seen as a luxury, and even travelling there was unaffordable.

When I wanted to do the gym, I couldn't afford to keep going by bus. It's £3 or £4 so money does play a big part (female, 30, Pakistani, diabetes).

Some gyms charge £40/month, some charge £30... I couldn't afford that (male, over 70, Pakistani, diabetes).

I: So if I was your doctor and I advised you that you should go to the gym to do more exercise and you had to pay gym membership of £20?

R: No, I'm not going to pay that [...] I feel uncomfortable paying £1.50 [for yoga] so I wouldn't pay that. Once I've taken the money out and budgeted it becomes very difficult (female, 38, Pakistani, diabetes).

The cost of travel similarly arose as a barrier when it came to attending health appointments, which sometimes resulted in participants missing appointments altogether if they could not afford the bus or taxi fare. One participant mentioned the inconvenience of early morning hospital appointments since she could only use her bus pass after 10am (female, 69, Indian/Kenyan, diabetes). An indirect financial consequence of attending frequent health appointments involved taking time off full-time employment and working time in lieu for one participant:

It does impact on my finances a lot actually cos I have to take quite a lot of annual leave or take what's called time in lieu. I have to work extra hours to build the hours up in order to take those other hours for my medical visits (male, 40s, African, diabetes).

Managing their diabetes through maintaining a healthy diet was sometimes difficult for participants as they perceived healthier food to be more expensive. In some cases, this was exacerbated where participants' welfare benefits had recently been reduced or where participants were in insecure employment.

I: In terms of a healthy diet, do you have enough money to be able to buy healthy food?

R: Sometimes I have, sometimes I haven't. They've cut some of my benefits...

I: So do you have to cut back in certain areas?

R: Of course. If you haven't got enough money then you do have to cut back.

I: Does that apply to food as well?

R: Well before we used to buy a lot of fruit, but we buy less now (female, Pakistani, over 60, diabetes).

I'm worried that when I leave work my financial situation won't be very good [...] if you look at a recipe you have to buy various ingredients and they can be very expensive so you have to think about it carefully (female, 61, Pakistani, diabetes).

We try a little bit to eat better food but on the whole the healthier foods are more expensive (male, over 70, Pakistani, diabetes).

Where maintaining a healthier diet was seen as too expensive, participants often made alterations to their existing diets which were more financially viable (cooking with less oil, for instance):

I: Do you feel you've got enough money to purchase such [healthy] foods?

R: That's so expensive, I don't buy that. Our own food like saag, dhal, curry base, I don't put much oil in [...] that's the kind of stuff I watch carefully (female, Pakistani, diabetes).

Participants inferred that managing their long-term condition (through attending appointments, maintaining a healthy lifestyle) came at an unanticipated expense. Maintaining a healthy lifestyle and following self-care advice involved strict budgeting and often became a matter of prioritising between paying for travel to appointments, attending the gym/exercise classes, and purchasing healthy food. For participants who did not drive, travel to and from health appointments (especially where they could only reach an appointment by taxi) was prioritised above spending on other aspects of a healthy lifestyle, such as gym membership and healthy food.

I go to the appointment, I don't cancel those... But then I make sure I spend a bit less on my food (male, 64, Pakistani, diabetes and asthma).

I: And it costs money to go to the gym, buy trainers?

R: Yes, that's right.

I: So you spend more money to manage your health?

R: Yeah, that's right (male, 58, Pakistani, asthma).

Enabling factors

Participants were keen to access services and maintain a healthy lifestyle but were, in many cases, prevented from doing so due to financial barriers. Given that the cost of exercise classes and gym membership (as well as travel there) was cited as a major barrier, several participants would have liked to have seen more exercise classes and gyms set up within community settings at a reduced fee. Participants had attended subsidised services in the past that had since closed:

Our local health centre did concessions for people with diabetes where they could go for free or it was heavily subsidised with a referral from the doctor but they don't do that anymore (female, 66, Bangladeshi, diabetes).

Participants who held a free bus pass valued accommodating appointment times which fit in with the times they could use the pass to travel. Participants may have benefited from further advice on how to cook healthy meals at a reasonable cost, since their perception was that healthier ingredients were unaffordable.

8.3. Work, caring and family commitments

Barriers

In many cases, participants were the main or secondary carer for a partner or relative, which often conflicted with the time they had available for attending health appointments, attending other services in the community, and maintaining a healthy lifestyle. Women, in particular, were often caring for more than one family member, and if they were a parent in addition to that, it left little time for self-care.

I: Have you ever been to a self-help group to help you manage your condition?

R: I haven't been [...] it depends because I have to look after my grandchildren (female, 73, Chinese, diabetes).

I'm a single parent and she's just turned six and I'm job-searching and I've got an elderly mother who I'm a carer for so it's draining me and you almost feel guilty making time for yourself, especially when there's time restrictions [...] Even exercising, I do my best to drop my child off and attend a class in-between but there's so many other things and commitments and it's always at the back and you miss out (female, 41, Pakistani, borderline diabetes and asthma).

I'm trying to get into work. At the moment I'm doing training, working with disabled kids, pick them up and take them to school and get back and take her to nursery and then go back to work and at home I look after mum. Don't really get chance to do much (female, 30, Pakistani, diabetes).

Participants who worked full-time also struggled to attend educational programmes such as Juggle:

They asked me to attend but I chose not to cos I have to go to work (female, 61, Pakistani, diabetes).

I'm a father, I'm a husband, I work 9-5 for the local authority [...] I attend quite a lot of appointments and the council luckily are supportive but they do frown upon it, particularly if you work frontline services [...] sometimes it would imply me going into work and then having to excuse myself from work for half a day to come back [...] sometimes I end up having to take annual leave instead so it does impact on you (female, 61, Black British, diabetes).

Enabling Factors

For those with caring commitments, having more flexible times for services, classes and appointments may make a difference to uptake. Providing affordable childcare facilities (like a crèche) at health and fitness services was suggested as one enabling factor:

It's a shame that gyms and these places don't have a crèche, that's the biggest issue out there. [...] X has a crèche but you can't afford to do that. If you have to pay a fee for the gym and childcare on top of that, how is it affordable for those people? (female, 41, Pakistani, borderline diabetes and asthma).

Other participants who were busy with caring and family commitments valued frequent reminders prior to appointments:

They did send me loads of reminders and I did make an appointment and then I just forgot, cos I've got four kids. I'm so busy with them I just forgot, but this time I put it in my phone as a reminder, but they were really good, they did keep sending me reminders (female, 30, Pakistani, diabetes and asthma).

Despite some participants being carers themselves, it was often only due to the reciprocal support of family members that participants were able to attend health appointments and other services (explored in more detail in Chapter 7):

It's really good cos I have my mum and my mother-in-law so they'll help out, but if I didn't have them then it would be really difficult cos I'd need to make other arrangements (female, 26, White/Pakistani, diabetes).

Discrimination

Participants were almost unanimously happy with the service they received from health professionals and most had not experienced discrimination or felt they had been treated differently based on their ethnicity. There was one exception where a participant felt she had been discriminated against in the past based on her ethnicity, and this had shaped her current view of health services. A minority of participants had had negative experiences but attributed these to language barriers and lack of understanding of culture rather than discrimination related to ethnicity:

I don't think it's about being discriminated, I think it's a lack of understanding and it's cultural knowledge about somebody's culture [...] they do ask you a lot of questions, particularly if you're diabetic. They have to check certain things [...] which could be quite intrusive so I find that culturally offending (male, 40s, African, diabetes).

The doctor said some time ago, "how long has it been since you came here?", "why can't you speak English?" I said "I've just come here" (female, Pakistani, respiratory condition).

It's their way of talking as well sometimes (male, 65, Pakistani, asthma).

It's difficult to think is it cos I'm Asian [...] but it makes me think all those people that do have language barriers and are pushed away, how badly they suffer (female, 41, Pakistani, borderline diabetes and asthma).

Cultural awareness and competency of health professionals

Key Findings

- Participants were mainly satisfied with health professionals' level of understanding of language, religious and cultural needs, although a few participants expressed concerns that health professionals only understood basic cultural and/or religious needs.
- Some health professionals were reported as having minimal understanding of the broader diets of different communities when providing advice, therefore limiting the impact of their recommendations.
- The diabetes educational programme – Juggle – was cited as an example of good practice for its cultural sensitivity in providing bilingual trainers and educational content tailored to reflect the diets of the communities engaging with the programme.
- The diversity of BAME groups in Nottingham City, which has expanded in recent years, is not necessarily reflected in the cultural awareness training that is provided.

9.1. Introduction

A number of studies referred to in the literature review revealed that the level of cultural awareness and competency of health professionals influenced how well BAME communities engaged with and took up long-term conditions services (Whittemore, 2007; Brach and Fraserirector, 2000). Chowbey *et al.* (2008) reported that English-speaking BAME people felt that health professionals misinterpreted the information they had shared with them, and this was attributed to a lack of cultural awareness and sensitivity. Those professionals who were keen to meet the needs of BAME people expressed uncertainty and a lack of confidence when attempting to do this due to a lack of training. They also raised the issue of health professionals basing their judgments on generalisations and stereotypes of different communities. All of the issues highlighted pointed to the need for ongoing cultural competence training and a diverse workforce representative of the communities served.

9.2. Barriers

Participants were mainly satisfied with health professionals' level of understanding of language, religious and cultural needs. Comments such as *'being listened to'* and *'they've met his [son's] needs all the time'* (male, 8, Bangladeshi, asthma) were repeated in several accounts. Conversely, a few participants expressed that health professionals only understood basic cultural and/or religious needs, *'they're ok... Not great'* (female, 37, Pakistani, diabetes).

Cultural awareness was not perceived as being necessary within the doctors' or nurses' roles, by a handful of participants - nurses, for example, were described as being responsible for doing routine checks, for which they did not need to be aware of any cultural issues. Health professionals were described as being 'too busy' in their roles, so there was little expectation of them to increase their awareness on the diverse needs of the range of communities in Nottingham.

Nevertheless, a different view was expressed by numerous participants, particularly in relation to language difficulties, which were not dealt with adequately by the doctors involved. In the following examples, language difficulties led to unresolved issues and in all instances patient needs could have been better met. In the first example, the participant's daughter recognised that she had to advocate on her mother's behalf or *'she would never get what she needs on her own'* (female, 63, Bangladeshi, diabetes); in the second case, the participant had stopped asking for help because her needs were not being understood and/or responded to as she would have liked; and in the third instance the participant felt that the doctor was dismissive, and her repeat appointments due to her health issues not being understood and resolved were viewed by the doctor as unnecessary:

She don't have the English level to explain to the doctor so she's just not asking. Once she see the doctor she cough and she have asthma and she wanted the doctor to give her medicine but the doctor won't, the doctor ask her to just do the inhaler (female, 63, Chinese, diabetes and asthma).

R: Sometimes the doctor horrible.

Interpreter: When she asked for help on something and the doctor just say 'you're fine, just go' say you're normal, you're fine.

I: But she doesn't feel fine?

Interpreter: She doesn't think so.

I: How does that make her feel?

Interpreter: She thinks it's just because she's often going to see the doctor and the doctor thinks you come too much, you're fine.

I: Can you give me an example of when your health needs could have been better understood by your GP?

R: Yes twice, but that was down to translation [meaning interpreter], there was no translator booked so we just managed to use online translation when doctor asked me the question and I could answer only yes or no so that was limited (female, 55, Polish, respiratory condition).

The above narrative highlighted how another participant's language needs were not met sufficiently; instead the doctor's use of online interpretation largely restricted what she could say; hence, only a partial picture of her health problem was presented.

Another interview highlights a situation where a participant was fortunate to see the same doctor consistently who was able to understand their patient's health history and meet their cultural needs. This was difficult to sustain where patients had to see different doctors each time they had an appointment:

I see him so often, he speaks our Mirpuri language, he understands everything as a family doctor. For 21, 22 years since I've been in this country he's been my one doctor, at first he was fine but since then place after place after place there are different doctors (female, 38, Pakistani, diabetes).

While the doctor often shared the same language, culture and religion as patients, some English nurses were identified as having cultural insight, which had been built up through experience. However, a couple of examples suggested exercising caution when drawing on cultural knowledge based on assumptions and generalisations, which might be incorrect and inadvertently be perceived as pathologising culture. Collectively categorising people from specific ethnic groups as adhering to a particular diet was problematised:

I: So the healthcare professionals that support you with your diabetes, do they understand your language, cultural and religious needs?

R: I think the Pakistani doctor does and the religious needs, the nurse, I think the nurse understands cultural needs cos they meet people from our communities all the time, every time they say in terms of Asian culture it's the food that's the problem, that's their first comment, cos this is Asian food and that's why you've got diabetes (female, 61, Pakistani, diabetes).

They don't know if we're still eating the same sort of things but they just assume we do, they assume you eat a very high spicy, salty diet and fatty foods and they couldn't be more wrong on that point (female, 55, Black British, diabetes and asthma).

Another account sent out an important message about how identity was shaped by the foods people ate culturally, and how integral culture was in people's lives, emphasising the need to preserve it and to approach the subject of diet with sensitivity when suggesting changes:

Culturally if you take away food from somebody it's like you're depriving them from their own culture so culturally it's quite key to some individuals, so taking that away is like taking a big chunk of their culture, it's very difficult (male, 40s, African, diabetes).

Some health professionals were reported as having minimal understanding of the broader diets of different communities when providing advice, therefore limiting their recommendations. Their inadequate knowledge of the types of food eaten, the ingredients, and how they were prepared, restricted advice in terms of adapting foods for healthier diets:

I: Does that doctor have enough understanding about the kind of foods you might eat?

R: I think she just tell her cos she know Chinese people eat a lot of rice, just tell her do not eat too much rice (female, 68, British Chinese, diabetes).

I don't think that nurse would have been able to say to me "do your dish in this particular way", I had to go away and educate myself the best way to live with my diabetes (female, 63, African Caribbean, diabetes).

It's generally very difficult as a BAME cos as a Black person I don't think it's culturally tailored to our individual needs so it's quite difficult, cos they don't understand about our food, so in training like that they talk about what pizzas you can eat, what sizes and stuff like that, so it's not in culture so it's quite difficult (male, 40s, African, diabetes).

Apart from diet, other cultural and religious practices were highlighted as not being understood sufficiently. This was demonstrated when a participant recounted his experience of seeking medical advice while fasting. While he acted upon the nurse's advice and broke his fast, the participant questioned whether a health professional with cultural knowledge might have provided him with options that allowed him to keep his fast:

I was fasting and I happened to go to the clinic so I had a test and the diabetic nurse said to me I needed to open my fast, I shouldn't be doing it because health wise it wasn't advisable, so I thought yeah I had to keep to what they were saying but I think if it was somebody that had a similar culture they would possibly understand and possibly support me in terms of possibly keeping the fast (male, 40s, African, diabetes).

A lack of cultural and religious awareness by health professionals when making referrals to other groups and activities was illustrated in a different case. In this situation, the practitioner might have been unaware of the environment in which the meetings took place, but nevertheless, as the participant's narrative indicates, this negative experience may have deterred her friend from accessing any other provision:

A friend of mine was referred to go and the Slimming World she went to had a bar area and she said as a Muslim I'm not comfortable going there and that put her off so much she never went again. When people make these referrals they should consider religion, culture before doing those referrals, cos if the initial referral is wrong a person will not go anywhere else and people give up (female, 41, Pakistani, borderline diabetes and asthma).

The diabetes educational programme – Juggle – was cited as an example of good practice with for being culturally sensitive in providing bilingual trainers and educational content tailored to reflect the diets of the communities engaging with the programme. Yet one participant underlined a gap in provision in relation to her religious needs, and possibly an oversight by the organisers:

There were no prayer rooms. The programme was for hours and I noticed that it was nearing Namaz [prayer] time but there were no prayer rooms around – this should have been there (female, 57, Pakistani, diabetes).

There was some evidence, from the stakeholder interviews, that not all healthcare professionals had received cultural awareness training – despite feeling they would gain benefit from receiving it. Two professionals who had undertaken the training felt it could have been more comprehensive, providing more detail on the population sizes of certain ethnic groups, cultural values, beliefs, and the language needs of the various ethnic groups constituting Nottingham City:

I wouldn't say the training went into much detail about the specific groups, it would have perhaps been more beneficial so we knew locally those figures and a bit more about the groups, but it was quite generic awareness, not much talk of interpreting and language either.

Several respondents acknowledged that the diversity of BAME groups in Nottingham City, which has expanded in recent years, is not necessarily reflected in the cultural awareness training that is provided.

9.3. Enabling factors

As stated earlier, participants expressed satisfaction with the basic level of religious and cultural awareness shown by their health professionals, one commented, *'they've always shown me respect in relation to my religion, the nurses and the doctors'* (female, 61, Pakistani, diabetes). Others felt their cultural needs were met by being able to see a female doctor:

Whenever she's asked for a female doctor at the hospital they've always offered her (female, 63, Bangladeshi, diabetes).

It's your own choice, you can say to them I'd like a female doctor or whatever. They're very good (female, 64, Pakistani, asthma).

They're quite sensitive cos they'll ask if she needs a female doctor, they'll provide a female doctor, it's been like that since the beginning (female, 66, Bangladeshi, diabetes).

Those participants in contact with healthcare professionals from their own religious and/or cultural background were fortunate to have their needs understood more fully due to shared language, culture and in many cases, religion. Doctors informed other staff about specific patient needs too – for example, with language – and this was illustrated in the following example:

The doctor's already told them [health care staff] that I don't understand English so when I go there are also Pakistani girls there so when my daughter's not there I ask for an interpreter and they arrange for one (female, 60, Pakistani, diabetes).

Several participants reiterated that they found it easier to fully explain their health matters to doctors and/or nurses who spoke the same language, and felt reassured knowing that they had understood:

For other people because you see all these Asian nurses and doctors I think it's quite useful for them (female, 26, White/Pakistani, diabetes).

When I came here [to the UK] there were not many Asian doctors and I did feel I couldn't explain an illness and then after some time it got better and there were Asian doctors...you can explain yourself better and you know the doctor's understood' (male, 58, Pakistani, asthma).

I found it easy because my doctor speaks in my language and not in English (female, Pakistani, diabetes).

I: Ok. You said your GP is an Asian and understands your language. Does she understand your culture or religious requirements?

R: She is a Muslim herself. She understands everything (female, 57, Pakistani, diabetes).

In instances where the cultural backgrounds of health professionals were similar to those of their patients, they had a better knowledge of their patients' cultural practices, diets, and in some cases spoke a language or dialect close enough to that of their patients to be able to communicate effectively with them. These cultural commonalities allowed advice to be tailored to patient needs rather than generic, as illustrated by the subsequent example where a Malaysian doctor was able to provide more detailed explanation about the Chinese diet:

Even if it's English doctor they will still ask you to have a different diet, more healthy, less sugar, not specific like the Malaysian doctor, the Malaysian doctor was able to explain a little bit details (female, 68, British Chinese, diabetes.)

Culturally inappropriate referrals by health professionals were cited as a barrier to the uptake of health services earlier, but equally, referrals to culturally appropriate services were highlighted as demonstrating health professionals' awareness of specific needs:

I: How well do you feel that the GP and community nurse knows or understands any cultural or religious needs?

R: Yeah she does cos when she referred me for Juggle she referred to the Asian group cos Asian cooking's obviously different to English cooking, she asked me what would I prefer, the Asian one or the English one and I said the Asian one cos we make Asian food (female, 30, Pakistani, diabetes and asthma).

An interview revealed that health professionals could learn a great deal from their patients and increase their cultural awareness by listening to them. In this example, when a participant challenged the nurse on dietary information and food preparation the nurse took the learning on board:

I: We talked about the cultural awareness of the health professionals, can you give me any examples of when your needs were met really well by them culturally?

R: No my need has never been met culturally by them, if anything doing those sessions with the specialist nurse, I had to challenge and clearly say for me culturally this is how I do my meal, this is how I do my potatoes.

I: So educating her in that process?

R: I have indeed, I've had to literally educate them and just to remind them that it's nice to have this insight but at the end of the day I don't eat that and this is what I eat and it's nice to know that she's taken on board what I was saying (female, 63, African Caribbean, diabetes).

Practical demonstrations by health professionals on how to use inhalers for asthma conveyed a level of cultural competency. Although such demonstrations are useful for all ethnic groups, they are particularly helpful for those with language difficulties. This was reinforced by the following account:

I: Can you give me an example of when you felt your needs were really met very well?

R: If I see my GP about another health issue she'll look at my records and said it's been a while since your last asthma review and she'll do an asthma review there and then, she makes sure I've got my inhaler with me, she'll ask me to demonstrate how I'm using my inhaler and makes sure I'm using it correctly and things like that (female, 48, Black African Caribbean, asthma).

When one participant provided her thoughts on how to increase the uptake of respiratory conditions services, she cited a nurse in an example of good practice, whereby she took a whole family approach to educating them about a health condition. Acknowledging that, culturally, some people cannot, or are not comfortable to, leave their homes, she took her services to them, simultaneously educating several members of the same family:

Anything as simple as calling a health professional and maybe putting a date at a community centre and saying we're having this evening where we're going to be teaching you about asthma and this and that, or alternatively for people who can't come out, cos that can be a problem in some cultures, maybe going to them... I had a lovely nurse who came out and she trained us... she asked me beforehand is there anyone in your family who you want to know about this and I said yes cos people don't understand (female, 28, Bangladeshi, asthma).

Case studies

10.1. Case Study 1: Adama (pseudonym)

Adama is a male in his 40s, of Gambian ethnicity, who has been living in the UK with his family for 16 years, and is currently residing in Sneinton. He was diagnosed with Type 2 diabetes approximately two years ago. He can read and write in English and in three other Gambian languages.

Initially, his diabetes was managed through diet, but he was put on medication six months ago. His condition has several repercussions for his cultural practices – for instance, the family can no longer observe the practice of sharing food and eating from 'the same plate'. Diabetes has an impact on Adama's lifestyle, financial situation, and wellbeing:

What I can eat and can't eat, it's very difficult as an African and as a Gambian as well, rice is our staple food and because of the amount of starch that is in rice I have to cut down on the amount of rice intake I have and getting the right portion is very difficult, what ingredients you use as well. It's quite expensive as well in terms of what you have to eat, like you have to buy certain products that you're allowed to eat and certain things you can't eat as well and sometimes I feel quite tired physically.

A number of services are used to manage his diabetes, including the doctor for a six month check-up; a three monthly visit to the diabetes clinic; and an annual eye test to check for glaucoma. Adama has researched his condition on the internet and learnt about it through the Juggle Diabetes Service. When asked about his experience of this service, he reported:

It was quite helpful cos they give you an insight of the contents that are in certain products, particularly when it comes to food, the ingredients that you have to look for on the labels, the other thing is realising you're not the only one with diabetes and hearing other people talk about their experiences or how they manage

While Adama recognised the overall benefits of undertaking the Juggle course, he also felt that the foods used to illustrate portion sizes and other dietary information did not reflect his cultural diet:

It's generally very difficult as a BAME cos as a Black person I don't think it's culturally tailored to our individual needs so it's quite difficult, cos they don't understand about our food, so in training like that they talk about what pizzas you can eat, what sizes and stuff like that, so it's not in culture so it's quite difficult.

He pointed out that even the examples of juices used to demonstrate the sugar content were unlike the juices he purchased from African shops, and therefore, it was difficult for him to gauge the quantity that he should consume. The trainers were unfamiliar with other spices and oils used by Gambian people and were unable to advise on correct quantities.

According to Adama, health professionals do not always understand patients' cultural needs or approach cultural issues with sensitivity. He provided an example to substantiate this view: last year when he saw the Diabetes Nurse he was fasting and was advised to break his fast due to his health condition. Although he followed her advice he questioned afterwards whether a health care professional with a similar culture to his might have supported him to keep the fast. Apart from this experience, the Diabetes Nurse was described as welcoming, supportive and 'always willing to listen' and this was important for building patient-professional trust.

Adama suggested the use of 'cultural ambassadors' to help address health issues within minority ethnic communities. These would be ambassadors that BAME people could relate to, with relevant cultural insight to engage effectively with minority communities:

Having cultural ambassadors are quite important in this, if you have a middle class person go to certain communities and want to talk to them about certain illnesses they always think it's got nothing to do with me, but training people from different communities to go and talk to those people in that community who possibly understand and accept them or welcome them far better.

10.2. Case Study 2: Ayesha (pseudonym)

Ayesha is female, 41 years old, British Pakistani, a single mother of two children, living in The Meadows with her mother. She has had asthma since the age of 16 and was diagnosed as a borderline diabetic approximately three years ago. Her main spoken languages are English and Urdu and she can read and write in these too.

She researches her health conditions using the internet and reads information in leaflet form:

I think leaflets are brilliant cos if you pick up a leaflet and you've got it at home, sometimes you want to go back to something, you have that in front of you and it's a lot better as long as the jargon that's used is not too medically termed, but I think leaflets are a lot better.

On the whole, her asthma is well managed and therefore has limited impact on her wellbeing. The General Practitioner (GP) monitors Ayesha's health through a six monthly check-up and the Community Nurse has provided dietary information - '*she's given me leaflets on diabetes and especially what to eat, what foods to cut down on*'. As a result of an Exercise Referral scheme to the YMCA, Ayesha was able to lose weight, but just as she got into the flow of exercising, the three month duration of the referral ended. Unfortunately, Ayesha was unable to afford the membership fee to continue.

By playing a pivotal role in setting up a diabetes self-help group she then used this arena to lobby for the Juggle course to become available for people with borderline diabetes. In Ayesha's view, self-help groups are beneficial but should be for specific communities due to their shared cultural beliefs, practices, and issues:

Self-help groups can be good and I know they're a success, the other project, the Muslim Women's Organisation where I was doing voluntary work; they had

a self-help group, with the Asian community if they go to a self-help group they will need something that's specifically for the Asian community cos you have language barriers, cultural issues, even dietary issues.

Drawing on her previous experience as a Health Trainer, Ayesha expressed that health professionals in general, lacked cultural awareness and misunderstood the needs of BAME people, for example, providing interpreters where patients actually required somebody in the capacity of a chaperone to accompany them to initial visits when feeling daunted by the prospect of accessing new services:

When I worked as a health trainer, we did something similar to a buddying scheme where a woman... it was identified she needs to do the GP referral exercise scheme and thinks "no I've never been there... I can't exercise" and you say "don't worry, as a health trainer I'll go to a session with you", and they say "brilliant" and then they got used to it and we could back off.

Having battled to be eligible to undertake the Juggle course and won, Ayesha then encountered the rigidity of the programme when she tried to book a place:

I was told these are the days for Juggle, I had one hospital appointment I couldn't miss and they said you've got to do the entire days, with Juggle even sometimes unforeseen circumstances would happen to anybody so if they number the sessions, session 1, session 2 and if a person misses session 2 they should be able to go to another place that's doing session 2 and pick up there.

She is still waiting for a place on this course. Her commitments to family clearly impact on her ability to attend healthcare services:

Definitely, I'm a single parent and she's [daughter] just turned six and I'm job searching and I've got an elderly mother who I'm a carer for so it's draining me and you almost feel guilty making that time for yourself, especially when there's time restrictions.

10.3. Case Study 3: Sakina (pseudonym)

Sakina is female, 38 years old, of Pakistani ethnicity and lives in Hyson Green with her husband and three children. Her main spoken language is Mirpuri. She can speak and read Urdu and speaks a little English too. She was diagnosed with Type 1 diabetes a year ago, which she manages with medication and by paying attention to her diet. There is a history of diabetes in Sakina's family; she lost both of her parents to this condition and her two brothers and uncle live with it too. Whilst Sakina has accepted that she has diabetes, she is affected by it in various ways. For instance, she experiences changes in her mood and physical wellbeing:

Sometimes I feel very angry, I feel tired, I feel lazy, I feel like there isn't any energy left in my body and I feel weak. Sometimes I'm so happy I don't realise I've got it but sometimes I tell myself no, god tells you you should always stay happy.

Both the doctor and nurse are involved in Sakina's healthcare; they have been supportive so far, she commented, *'the nurse has helped a great deal, I'm very happy with her, she's helped me a lot, she's told me about the side effects of diabetes, she did a full check-up'*. Although the nurse didn't provide any dietary advice, she encouraged Sakina to attend the free exercise classes that she had referred her to, but she didn't take up this service. When questioned further, she

explained that her reluctance was partly due to how far the service was located, and also gave the following reasons:

Just it's about my own time. For example I found out about this research and I was just nearby so I turned up cos I thought I won't have to phone, I won't have to do anything, but usually my daughter, she's busy with her education and she has to make the phone calls for me and she'll say 'I'll do it today, I do it another day'.

Most of Sakina's diet is influenced by the foods she saw her parents eat when they were suffering with diabetes, or through her researching on the internet. Her cultural and religious beliefs have strongly influenced her diet, so much so, that she has reduced the medication prescribed by her GP:

No, adjuar date, it's advisable to eat adjuar dates and if you eat it in the morning it's good for diabetes. These tablets, I only eat my tablet that my GP gave me once a day cos the other time I'm careful and watch what I eat, adjuar dates, if you eat those they're very good for you. There are so many other foods that can make you feel better. Our religion provides a lot of knowledge for illnesses.

This reliance on alternative remedies is not helped by a lack of guidance on diet from her nurse. Each time Sakina has an appointment with the nurse she has to take her daughter with her to interpret, and this requires her daughter taking time off from school. Sakina used an interpreter when she first arrived in the country but doesn't feel the need to since having a Pakistani Mirpuri-speaking doctor. She explained that whenever she calls to make an appointment she asks if her doctor is available, and if not, turns the appointment down. She is aggrieved by the current situation at her surgery where each appointment is likely to involve seeing a different doctor.

When asked how she would like to receive health information, Sakina was resolute in her preference for face -to-face contact:

Then things can be explained properly. If you look at a leaflet you're not going to be particularly bothered by the information in it, you might think "let's not bother". With the radio, sometimes I listen to it, sometimes I don't, sometimes I'm busy. When you speak to someone face-to-face you normally have an appointment, you know you're going to meet that person, when you have to see your health worker you take time out to see them.

Having recently been diagnosed with diabetes, Sakina is trying to cope with her feelings and manage her diet. She receives practical support from her family, but there is little evidence of her emotional needs being met. Her positive response to attending a self-help group for diabetes, subject to there being one run in her local area, confirms that she feels isolated managing her condition alone:

Yes, a human being can't learn anything alone, there isn't as much support within the family, within the family you just have to do your duty, cook the food, there's no attention. When [it's helpful] you go and sit in such a place where you can sit down with other women and get advice.

10.4. Case Study 4: Patricia (pseudonym)

Patricia is female, aged 61, of African-Caribbean ethnicity, living in The Meadows with her husband. Her main spoken language is English. She has high blood pressure, osteoporosis, and was diagnosed with Type 2 diabetes approximately four years ago. Diabetes has impacted significantly on Patricia's diet:

You have to think about what you put in your mouth, how you prepare your food, I've cut out a lot of West Indian food such as try not to do no frying, no sweet potato, dumpling, I just try and do vegetable and vegetable to see if I can lose some of the weight and get rid of this diabetes.

Having diabetes, coupled with osteoporosis, makes Patricia 'depressed' since she is no longer as mobile as she used to be. She said, *'I feel as though I'm going to fall down and I don't want to fall cos I'll break my limbs, so it's very difficult'*. Due to her fear of falling, she is heavily reliant on her husband to go anywhere. This is difficult for Patricia to come to terms with, as she regularly went out independently before the onset of her illnesses. Without doubt, this reliance has a bearing on the services that Patricia is able to access.

The Diabetes Specialist Nurse does regular check-ups and offers valuable support, as Patricia reported, *'I feel comfortable with her cos she sits and talks to you and she has assured me that all that I'm doing is working so I feel better'*. Patricia also attends a monthly diabetes self-help group in The Meadows once a month. This group provides the opportunity to meet other people *'in the same boat'* and to learn more about diabetes – the symptoms; how to manage it; and its impacts:

They put on what you eat and what it does, different things, they talk about your eyes...I find it's good cos I can talk to people; hear what people say about themselves. I didn't realise this diabetes can do so much damage cos you can lose your limbs.

The Diabetes Specialist Nurse and the self-help group is easily accessed by Patricia, because these services are based in the local area. As Patricia commented, *'I feel comfortable going there'* and *'I walk to it, it's in the community and I find it's very good at the health centre with them having a diabetes nurse'*.

10.5. Case Study 5: Maria (pseudonym)

Maria is female, aged 46 years, of Polish ethnicity, and has been living in St Ann's, in Nottingham, with her husband and granddaughter for just over 5 years. She was diagnosed with bronchial asthma 17 years ago, and she also suffers from scoliosis. Polish is her only spoken language, and she can read and write in it also.

Maria manages her condition by using an inhaler; a new prescription is required every month. She also sees her doctor/nurse every three months. Asthma affects her day-to-day life significantly:

I feel very tired and I'm sometimes even scared of attacks, they make me feel very weak, I can't do activities – for example tidying up the house, climbing up and down stairs, going out even. And also I have scoliosis which combined with asthma effects. My whole immune system is weaker so even smallest cold I get it quite severe and I get infected much easier than other people.

Her condition is so severe that she has an asthma attack at least once a month. She believes that her condition is deteriorating, but each time she asks to see the doctor is given an appointment with the nurse whom she feels *'may not be qualified'* to diagnose and treat her changing health situation. The nurse does a routine test to check Maria's lung capacity but does not explain her condition with her in enough detail, Maria believes - *'here no-one ever discuss my condition with me, neither the nurse or GP'*.

The use of an interpreter to attend appointments also presents challenges for Maria. Her experience varies depending on the interpreter:

Very often I have a feeling interpreters don't translate everything I say, cos sometimes I may say quite a few sentences and he will repeat maybe half of it. Also very often when I say something to the doctor or I reply to the doctor the interpreter is engaging conversation with me instead of, like saying 'oh really?' or doubting that it can be the case instead of being only an interpreter.

Maria highlighted that the time constraints of interpreters sometimes inadvertently put pressure on her to rush through the appointment. As she stated, *'very often before we even get to the doctor I hear from an interpreter that he or she has got different arrangements somewhere else in the city and it's very stressful'*. In such situations, Maria skips any additional questions, knowing the interpreter is in a hurry.

Whilst Maria is able to rely on *The Signpost to Polish Success* organisation to provide support with translating any health correspondence that she has, she pointed out that health booklets and leaflets on her condition are not available in Polish. Instead, her husband helps her to translate any information the best he can.

Maria has not accessed a support group for her asthma, but when the principles of such a group were explained to her, she responded with enthusiasm:

I would very much like to involve in such a group cos I can listen other people's experiences and the way they deal with their health conditions so that would be very useful for me.

Maria's story illustrates various barriers to taking up services, which are ongoing. The health professionals that she has been in contact with have not understood her needs, nor have they made efforts to find out about Maria's culture and how this might influence her health. While her experiences of accessing services in Nottingham City for her respiratory condition are – on the whole – satisfactory to her, some aspects of her healthcare story in the UK have undercurrents of discrimination:

It may be due to the fact that I come from Poland and what my background is, but I do feel like there is some negative intention in terms of my presence, especially with one particular nurse, but other staff seem to be respectful.

Conclusion and recommendations

This report has discussed in some detail the empirical findings of qualitative research that explored the uptake of primary and community diabetes and respiratory long-term conditions services in Black Asian and Minority Ethnic (BAME) communities in Nottingham City. It has focussed on barriers and enabling factors from the perspective of a broad range of BAME communities to support NHS Nottingham City CCG and their local statutory partners to develop effective commissioning strategies in response to historically low awareness and uptake of these services. In this final section we revisit the original research questions to provide an overview of the key findings from the study and make recommendations for the CCG to consider moving forward. Question 1 is concerned with the main conclusions from the research whilst questions 2-4 focus on learning, recommendations and next steps.

1. What are the blocks and barriers to people from BAME communities with long-term conditions accessing and taking-up existing long-term conditions services?

The research has identified a number of factors associated with the uptake of long-term conditions services by people across Nottingham's BAME communities¹. These factors can be both *barriers to* and *enablers of* service uptake, depending on whether and how effectively they are addressed.

Language and communication

Poor English language skills were found to be a significant reason for the low uptake of services as these affected an individual's ability to communicate with health professionals about their condition(s) (and vice-versa). Where people had regular contact with health professionals who spoke their first language they were able to access services with greater ease. Although communication in a person's first language was always preferable good quality translation was found to be an effective alternative but, conversely, where translation was of a lower quality and consistency this was found to inhibit service use and understanding. Many people did not use interpreters, relying instead on family members to communicate with health professionals on their behalf and facilitate their engagement with services. When interpreters were not provided and family members were not available this could lead to insurmountable language barriers and a frustrating experience of engaging with health services that had negative consequences for people's management of their health condition.

¹ These are a series of overarching factors that affect the range of BAME communities in the City of Nottingham. However, at a community level these need to be understood in the context of the specific cultural and religious norms of those communities such as language, diet, routines and practises.

Awareness and understanding of health conditions

There was a general lack of awareness and understanding about the symptoms and management of long-term conditions which held people back from accessing primary and community services. Often these gaps in knowledge originated from the diagnosis process but were exacerbated by an ongoing lack of information about their condition and the importance of managing its symptoms. When people did access educational support and/or specialist services they had much more confidence about how to manage their health condition.

Provision of services

The flexibility and accessibility of services was a key concern for people with long-term health conditions. Providing convenient appointment times and delivering services and educational programmes in accessible locations were key factors in their uptake. People were keen to attend health appointments and broader services but these were more likely to be taken up if they were within easy reach of their home and could be fitted around their daily work, family and wider commitments. Services were viewed more positively and considered most effective when there was continuity of staff and where they had been attentive to specific cultural and religious needs.

Marketing and publicity

Information about the symptoms and management of long-term conditions was not typically offered to people in their first language and all correspondence relating to appointments, referrals and results was provided in English. This made such information inaccessible to people with poor English literacy but translated material could also be ineffective where people were illiterate in their first language as well, particularly when complex health information needed to be conveyed. Face-to-face contact with services, outreach workers and other native speakers with the same condition was a more effective and preferable way of learning about their condition for many people.

Sources of support

Although many people still viewed their GP or doctor as being best placed to support them with their health condition other important sources of support were also identified. *Within health services* this included specialist nurses, who tended to have more time to listen to people and provide emotional and practical support relating to their condition. *Beyond health services* this included family members, who played a significant role in providing emotional and practical help with the day-to-day effects of people's health conditions. It also included community resources, such as local community organisations, whose understanding of cultural norms and values created an environment of familiarity and trust where a broad range of help, advice and support could be accessed. Although there was a general lack of awareness of self-help groups, those who did participate in groups were positive about their impact, and many people not currently accessing self-help expressed an interest in getting involved in the future.

Overall, where people were confident and able to access support from a broader range of sources they were generally more effective at managing their condition independently.

Socioeconomic status and discrimination

Experience of discrimination was very uncommon but people's ability to maintain a healthy lifestyle was often affected by their financial situation. The cost of travel sometimes prevented them from attending health appointments and healthier food was often perceived to be more expensive. Where people had additional caring responsibilities this often limited the time they had available to attend health appointments, engage with wider services and maintain a healthy lifestyle.

Cultural awareness and competency of health professionals

People were generally happy with professionals' understanding of their language, religious and cultural needs but there were some specific examples where this could be improved. This included understanding the broader diets of different BAME communities and how these were shaped by religious practices and cultural norms, which limit the impact of dietary recommendations. The diabetes educational programme - Juggle - was cited as an example of good practice for its cultural sensitivity in providing bilingual trainers and content that was tailored to reflect the diets of different communities. However, more generally, the expanding diversity of BAME communities in the city is not necessarily reflected in the cultural awareness training that is currently provided to health professionals

2. How should the CCG, GP practices and service providers engage with BAME communities most effectively, including through an asset-based approach?

The research highlights the importance of co-production: involving people and communities in strategies and services that help them to manage and improve their health. People were most confident about managing their health condition when they were able to access effective support from health professionals in combination with support from family members, community organisations and/or self-help groups. As such, each of these different groups should be considered key stakeholders in the *engagement of* and *support for* people from BAME communities with health conditions.

The CCG's current strategy for developing local 'assets' to support and engage with people from BAME communities with health conditions and their families centres on growing self-help. Although there is evidence from the research that self-help groups are effective for the people who use them they are not being accessed very widely at the moment and there are a range of assets that could be utilised more fully. In particular, Nottingham City has a number of longstanding and trusted BAME community representative organisations with considerable *reach into* and *understanding of* the communities they serve. For many people in BAME communities these organisations are a first port of call for culturally sensitive advice, help and support and they are ideally positioned to play a central role in the engagement of BAME communities in co-produced approaches to support long-term health conditions moving forward.

3. What changes need to be made to the way services are delivered?

The findings suggest that Nottingham City CCG, with the support of its local statutory partners, have made considerable recent progress in transforming the way people from BAME communities are supported to manage long-term health conditions, in particular diabetes. As such, wholesale changes to the way services are delivered are not required. Rather, we make a number of recommendations about how this progress can be built upon and learning transferred to other service areas, such as

respiratory conditions, alongside some specific recommendations for consideration in a number of areas.

i. Broadening self-help and utilising a wider range of community assets

The CCG has made good progress developing and implementing asset-based approaches in recent years, in particular through its work with Self-Help Nottingham, but there is potential to broaden the reach and coverage of self-help yet further and raise awareness of self-help opportunities and their benefits. Self-help is most effective when groups reflect the cultural knowledge of the communities that they are targeted at, and run in the heart of local communities to ensure accessibility.

In addition, the CCG could make more effective use of the many BAME community organisations in Nottingham City to engage with seldom heard individuals in these communities and support them with their health needs. However, many of these organisations are very small and operate with limited funds, so any plans to utilise them more widely should be incorporated within wider commissioning and engagement strategies to ensure that their involvement is appropriately resourced.

ii. Increasing the diversity and improving the cultural competency of the workforce

The research identified the diversity and cultural competency of the workforce as a barrier that prevented some people from BAME communities engaging with health services effectively. The CCG should therefore consider a contracting approach with its providers that promotes workforce diversity for specific services so that the people delivering services are more representative of the communities they are required to support. Linked to this, people sometimes felt that staff lacked the cultural and religious knowledge and language skills necessary to engage with them effectively. As such, it is recommended that the CCG review with their providers policies around 'cultural competence' training, for although it is mandatory for many staff in health settings it is not updated on a regular basis. Doing so would ensure that cultural competency and awareness is embedded across primary and community services.

iii. Improving awareness and accessibility of primary and community services

Awareness of primary and community long-term conditions services was generally low. Although most participants engaged with GPs, practice nurses and specialist services in support of their condition, many did not engage with the wider suite of services available to them and did not have sufficient information about how and where to access these services or why they would be beneficial. As such, the CCG should consider a strategy for raising awareness of services from the point at which a diagnosis is made that utilises a variety of channels that are appropriate for the BAME communities they need to target. Rather than written and visual materials, consideration should be given to raising awareness through community organisations and radio, outreach workers and religious leaders.

In addition, the research found that health services and information were often not sufficiently accessible to people and this could limit their ability to engage effectively. This included the language barriers associated with accessing and communicating with health services and health professionals, the formats in which information was communicated, and the physical location of services when people had to travel considerable distances to access them. Overall it was felt that health services would be more accessible if they were better tailored to patients' personal circumstances. As such, the CCG should consider how it can commission more accessible primary and community services in terms of *how* and *where* services are provided.

iv. Monitor uptake of primary and community services

The CCG is committed to increasing the uptake of primary and community services by people from BAME communities with long-term health conditions. However, data on the ethnicity of service users is not collected routinely or consistently across these services. This limits the ability to analyse and review the uptake of these services generally, or of specific services by specific BAME groups. The CCG and its partners should therefore consider developing a consistent approach to monitoring the ethnicity of service users and regularly analysing uptake of services to identify overall progress and any patterns associated with changes in strategy or service delivery.

4. What are the next steps for commissioners to support a sustained increase in uptake of long-term conditions services by BAME communities?

As a first step, in response to this research, the CCG will need to consider the implications of the key findings and the extent to which the recommendations above should be taken forward. However, this report also provides an opportunity to reflect on the CCG's overall strategy around asset-based approaches to health and engagement, and the progress made towards embedding an asset-based approach to primary and community services for BAME communities. In the interim report we drew heavily on the work of Morgan (2014) and Hopkins and Rippon (2015) to identify a series of principles against which progress by CCG and its statutory, voluntary and community sector partners towards implementing an asset-based approach to increasing the uptake of long-term conditions support in Nottingham City by BAME communities could be monitored and evaluated. Figure 11.1 (overleaf) draws on the key findings from the research to highlight progress against these principles to date and suggest a series of next steps towards greater implementation and integration of asset-based working.

Figure 11.1: Progress towards an asset-based approach to primary and community services for BAME communities in Nottingham City

	Underpinning principles	Progress made	Next steps
1 Prioritising	Prioritising approaches that emphasise building positive well-being and associated psychosocial resources.	The CCG has made asset-based approaches to working with BAME communities a strategic priority, as evidenced by its support for the development of self-help across the city.	A broader approach to asset-based working could be developed. This might involve expanding self-help provision across the city as well as involving a wider range of community level organisations in commissioned service delivery.
2 Involving	Involving individuals and local communities effectively and appropriately, for example by embedding the principles of co-production.	The CCG has proactively engaged BAME service users and community organisations in the development of recent commissioning strategies.	To continue engaging service users and community organisations in service development, ensuring the broadest possible representation of BAME communities and organisations, including from the hardest to reach and seldom heard groups.
3 Connecting	Connecting the individual with community and broader society, including through solutions and activities that utilise and develop voluntary organisations and community groups.	Through their work with Self-Help Nottingham the CCG is investing in a wide range of peer-led self-help groups for people from BAME communities across the city.	The CCG should promote as widely as possible referral from health services into the wider voluntary and community sector, building on its existing work on social prescribing.
4 Integrating	Working in a decision-focused, multi-professional and multidisciplinary way, including through integration of teams working in health, social care and community development.	Although the research did not explore integrated multi-disciplinary working we understand this has been a feature of primary and community care across the City since 2013.	To review the effectiveness of current integrated multi-agency approaches in the context of the <i>barriers to</i> and <i>enablers of</i> service uptake identified through this research.
5 Investing	Securing investment from a variety of sources (statutory and non-statutory) through a multi-method, evidence-based approach.	Current investment in asset-based working, such as the CCG's partnership with Self-Help Nottingham, draws solely on mainstream CCG budgets. Furthermore, the impact of asset-based working on service uptake by BAME communities is unknown.	The CCG should aim to broker the broadening of statutory investment in asset-based working to include, for example, Public Health and Adult Social Care, as part of city-wide multi-agency strategy for asset-based approaches. The impact of self-help on service uptake should be robustly evaluated.

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Appendix 1: Methodology



Evidence Review

The evidence review utilised a 'rapid evidence assessment' (REA) framework to examine the over-arching research question of *'what works in increasing the uptake of primary and community long-term conditions services in Black and Minority Ethnic (BAME) communities'*. This involved a review of academic, grey and practitioner literature, including, where relevant, evidence from overseas and from allied fields. Although the CCG's commissioning focus is on diabetes and respiratory conditions, the scope of the review encompassed other conditions, and long-term conditions as a broader concept, to ensure the widest range of evidence and learning was captured. Overall, the review identified a wealth of relevant literature associated with the *barriers to* and *enablers for* BAME people accessing health services for general long-term conditions as well as specific conditions such as mental health problems and diabetes. However, there was less evidence identified in the area of respiratory conditions, although the lessons from other conditions are transferable in many cases. In a separate exercise, key literature around the role of asset-based approaches in health and social care was identified and reviewed.

In total, more than 100 published papers, reports and documents were reviewed. An overview of the number of documents reviewed by theme is provided in table 2.

Table A1: Overview of evidence reviewed by theme

	Barriers	Enablers	Asset-based approaches	Total
No. of documents reviewed	91		17	111
No. of documents graded high for relevance and quality	18	21	n/a	39
No. of other documents reviewed	54		17	72

Note: some documents covered both barriers and enablers and are counted in both columns.

Stakeholder interviews

Following consultation with the Research Steering Group a number of key stakeholders were identified from across the voluntary and statutory sector in Nottingham City. Overall, 17 semi-structured qualitative interviews were undertaken with representatives from:

- the CCG, covering commissioning and service delivery
- General Practitioners
- Nursing

- Public Health
- the voluntary and community sector.

This element of the study had NHS research governance approval from Nottingham University Hospitals NHS Trust (Ref: 15RS004), NHS Nottingham Clinical Commissioning Group (Ref: 300615) and Nottingham CityCare Partnership. A copy of the topic guide is provided in Appendix 4.

Interviews with people from BAME communities

69 people from BAME communities across Nottingham City participated in in-depth semi-structured qualitative interviews with a member of the Research Team. The approach to recruitment, interviewing and data analysis is outlined below. This element of the study received ethical approval from the Sheffield Hallam University Research Ethics Committee.

Recruitment

Participants were recruited through two routes: local BAME voluntary and community organisations, and community radio.

Local BAME voluntary and community organisations

At the beginning of the study the Research Team, in partnership with the Steering Group, identified a number of local voluntary and community organisations serving different BAME communities. The Research Team then made contact with representatives of each organisation to introduce them to the project and secure agreement to support the recruitment process.

- Chinese Welfare Association
- Asian Women's Project
- Queens Walk Centre
- Gambian Community Centre
- New Art Exchange (African Focus Group)
- The Signpost to Polish Success
- Indian Community Association
- Self-Help Nottingham.²

Each organisation agreed to work with the Research Team to promote the research and identify potential participants from the people who accessed their services. In addition, a number of these organisations agreed to provide access to rooms in which the interviews could take place and community interpreters (when members of the Research Team did not speak an appropriate language). Recruitment typically involved a two-stage process:

- **Stage 1:** a visit to the organisation by members of the Research Team during a popular activity or busy period to meet people involved with the organisation and discuss the research with them on an informal basis. Contact details of potential participants were collected so that their involvement in study could be discussed further.
- **Stage 2:** further visits by the Research Team on a series of pre-arranged dates when the interviews would take place. Where possible participants were given a specific time

² Although Self-Help Nottingham supports people of all community backgrounds, not just BAME, they support a number of condition specific self-help groups for people of different BAME backgrounds.

for interview but in a number of sites a 'drop-in' system was also put in place to provide flexibility and maximise participation rates.

The majority of research participants were recruited through this route.

Community radio

The Research Team undertook additional recruitment activity through two of Nottingham's well-established BAME community radio stations: Kemet FM, which serves the African and Caribbean communities; and Radio Faza, which services South East Asian communities. For each station a short advert promoting the research was developed and Radio Faza also held a 'phone-in' devoted to issues related to the research. Through the advert and radio phone-in potential participants were provided with information about how to get in touch with the Research Team to discuss their possible involvement.

Overall recruitment

Overall, 69 people from BAME communities across Nottingham City were recruited to participate in the research. A summary of their characteristics is provided in table A2, with more detailed information provided in Appendix 2.

Table A2: Summary of characteristics of research participants

	User of community and/or long-term conditions services		Total
	Yes	No	
Gender:			
Male	8	6	14
Female	34	21	55
Age:			
Under 18*	3	0	3
18-40	6	1	7
41-60	10	7	17
61-75	14	7	21
Over 75	3	6	9
Not stated	6	6	12
Ethnicity:			
Pakistani	18	11	29
Indian	2	3	5
Bangladeshi	4	0	4
African-Caribbean	10	8	18
Chinese	5	4	9
Polish	3	1	4
Total	42	27	69

*People aged under 18 were not interviewed directly but several participated from the perspective of their child with an LTC.

Approach to interviews

When the interviews were undertaken a number of common principles were adhered to:

- **Method:** the majority of interviews were undertaken face-to-face. In a small number of cases participants chose not to be interviewed face-to-face and interviews were undertaken over the telephone.
- **Language:** all interviews were undertaken in the participant's first or preferred language. In cases where members of the Research Team did not speak this language interpreters were used.
- **Gender:** a mix of male and female researchers undertook the interviews. Participants were asked during recruitment if they would prefer a male or female interviewer and the preference was accommodated.
- **Duration:** interviews typically lasted between 30 and 60 minutes. Participants were able to stop the interview at any point.
- **Interview schedule:** a common interview schedule/topic guide was used but members of the Research Team use their discretion as to how assiduously this was followed according to the personal circumstances of each participant.

A copy of the interview schedule is provided in Appendix 5 with a copy of the participant information sheet provided in Appendix 6.

Approach to analysis

Analysis of the data collected involved a number of phases:

1. **Transcription/translation:** all interviews with people from BAME communities were transcribed. Interviews undertaken in non-English languages were translated and then transcribed. Each transcript was imported into the NVIVO software package prior to analysis.
2. **Coding:** each transcript was coded using a coding framework based on the interview schedule.
3. **Thematic analysis:** through the coding framework the data was analysed to identify a range of key themes evident in the data. Overall eight overarching themes were identified. Key quotes were identified to illustrate each theme and various sub-themes and to ensure the seldom heard voices of the research participants were brought forward through the research.
4. **Reporting:** for reporting purposes the themes were grouped around eight key themes which formed the basis of the main body of the research.

Appendix 2: Research participants



Reference	LTC Service user	Gender	Age	BAME background	Primary health condition(s)
1	No	M	72	Chinese	Diabetes (unknown whether Type 1 or 2)
2	Yes	M	81	Chinese	Diabetes (unknown whether Type 1 or 2)
3	No	F	78	Chinese	Respiratory condition (undiagnosed)
4	Yes	F	67	Chinese	Diabetes (Type 2)
5	Yes	F	73	Chinese	Diabetes (unknown whether Type 1 or 2)
6	No	F	64	British Chinese	Respiratory condition (unknown)
7	Yes	F	63	Chinese	Diabetes (unknown whether Type 1 or 2) and asthma
8	No	F	68	British Chinese	Diabetes (unknown whether Type 1 or 2)
9	Yes	F	81	Chinese	Diabetes (Type 1)
10	Yes	F	41	Pakistani	Borderline diabetes & asthma
11	Yes	F	30	Pakistani	Diabetes (unknown whether Type 1 or 2)
12	Yes	F	69	Indian/Kenyan	Diabetes (Type 2)
13	Yes	F	37	Pakistani	Diabetes (Type 2)
14	Yes	F	30	Pakistani	Diabetes (Type 2) & mild asthma
15	Yes	F	53	Pakistani	Diabetes (unknown whether Type 1 or 2)
16	No	F	49	Pakistani	Asthma
17	No	F	67	Pakistani	Diabetes (Type 2)
18	Yes	F	38	Pakistani	Diabetes (Type 1)
19	Yes	F	Unsure over 60	Pakistani	Diabetes (unknown whether Type 1 or 2)
20	Yes	F	60	Pakistani	Diabetes (unknown whether Type 1 or 2)

Reference	LTC Service user	Gender	Age	BAME background	Primary health condition(s)
21	Yes	F	42	Pakistani	Diabetes (unknown whether Type 1 or 2)
22	Yes	F	61	Pakistani	Diabetes (Type 2)
23	Yes	F	Guessed 64	Pakistani	Diabetes (unknown whether Type 1 or 2)
24	Yes	F	32	Pakistani	Asthma
25	No	F	35 daughter is 14	Pakistani	Interview on behalf of daughter who has severe asthma
26	Yes	M	64	Pakistani	Diabetes (unknown whether Type 1 or 2) and Asthma
27	No	M	58	Pakistani	Diabetes (Type 2)
28	No	F	64	Pakistani	Asthma
29	No	M	Over 70	Pakistani	Diabetes (Type 1)
30	Yes	F	71	Pakistani	Diabetes (Type 2)
31	No	M	58	Pakistani	Asthma
32	No	M	65	Pakistani	Asthma
33	Yes	F	55	Pakistani	Diabetes (Type 2)
34	No	F	26	South Asian/White	Diabetes (Type 1)
35	Yes	M	51	African Caribbean	Diabetes (Type 2)
36	Yes	F	41	Pakistani	Diabetes (Type 2)
37	No	F	80	African Caribbean	Asthma
38	Yes	F	80	African Caribbean	Diabetes (Type 2)
39	Yes	F	63	African Caribbean	Diabetes (Type 2)
40	Yes	M	10	White and African Caribbean	Doing interview on behalf of son who has severe asthma
41	Yes	M (and his wife)		Pakistani	Diabetes (unknown whether Type 1 or 2)
42	No	F		Pakistani	Diabetes (unknown whether Type 1 or 2)
43	No	F		Pakistani	Respiratory
44	Yes	F	61	African Caribbean	Diabetes (unknown whether Type 1 or 2)
45	Yes	F	63	African Caribbean	Diabetes (Type 2)

Reference	LTC Service user	Gender	Age	BAME background	Primary health condition(s)
46	No	F	80	African Caribbean	Asthma
47	No	F	54	African	Asthma
48	No	F	53	African	Asthma
49	Yes	M	40s	African	Diabetes (Type 2)
50	No	F	48	Black African Caribbean	Asthma
51	Yes	F	55	Black British	Diabetes (Type 2) and asthma
52	Yes	F	61	Black Caribbean	Diabetes (Type 2)
53	Yes	F	57	Pakistani	Diabetes (Type 2)
54	Yes	F		Gambia	Asthma
55	No	F		Ethiopia	Asthma
56	No	M		Gambia	Asthma
57	No	F		Nigeria	Asthma
58	No	F	70	Indian Gujrati	Asthma
59	No	F	79	Indian Punjabi	Diabetes (unknown whether Type 1 or 2)
60	Yes	F	46	Polish	Asthma
61	No	F	55	Polish	Respiratory condition
62	Yes	F	14 (father present)	Polish	Asthma
63	Yes	F	58	Polish	COPD
64	Yes	M	74	Indian British	Asthma
65	no	F	81	Punjabi British	Asthma
66	Yes	F	66	Bangladeshi	Diabetes (Type 2)
67	Yes	M	8 mother did the interview	Bangladeshi	Asthma
68	Yes	F	63	Bangladeshi	Diabetes (type 2)
69	Yes	F	28	Bangladeshi	Asthma

Appendix 3: Sample health leaflet

A3

Clinics

1. Boots, Victoria Centre, Lower Parliament Street, Nottingham NG1 3QS
2. St Ann's Valley Centre 2 Livingstone Road, St Ann's, Nottingham NG3 3GG
3. Clifton Cornerstone Southchurch Drive, Clifton, Nottingham NG11 8EW
4. Bulwell Riverside, Main Street, Bulwell, Nottingham NG6 8QJ
5. Sherwood Health Centre, Elmswood Gardens, Sherwood, Nottingham NG5 4AD

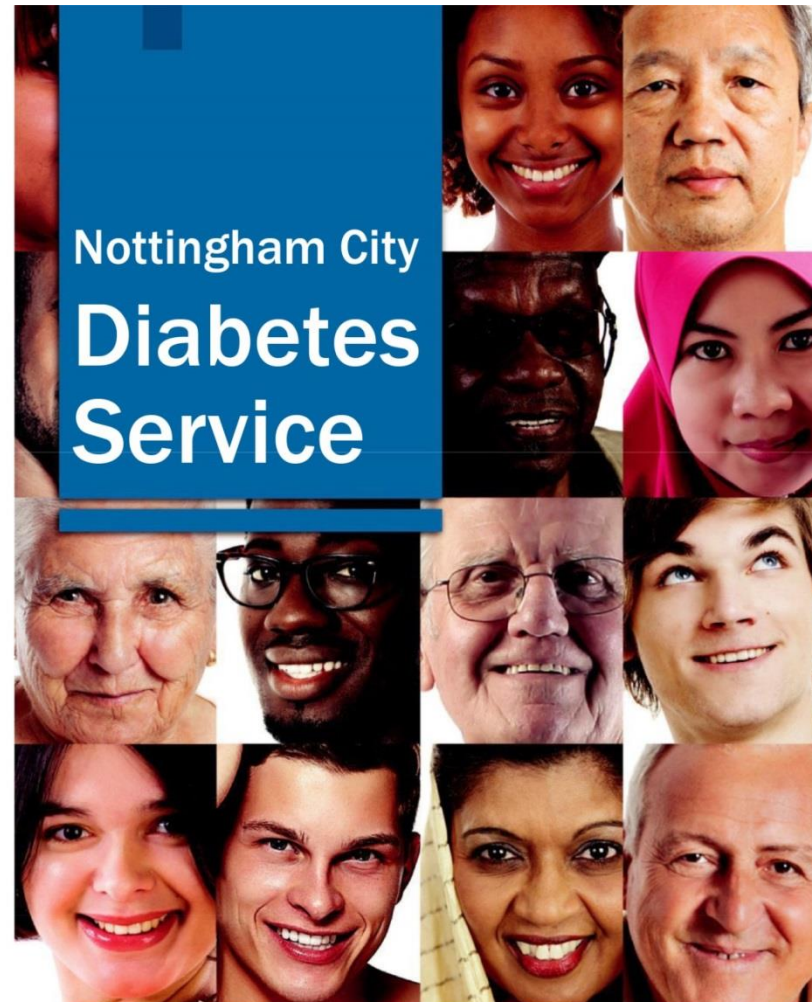


Alternative venues may be available, please ask.

For more information telephone Nottingham City Diabetes Service on **0115 883 9800** or visit www.nottinghamcitycare.nhs.uk

Tell us about your experience of our service

You can feed back any compliments, concerns, complaints or comments by: Telephone: 0115 883 9654
Email: customer@nottinghamcitycare.nhs.uk
www.nottinghamcitycare.nhs.uk/get-in-touch/



A guide to services in Nottingham City, for people with Type 1 and Type 2 diabetes and their carers



Learn more about your diabetes.

A variety of education programmes are available.
To find out more or to book call: [0300 300 0045](tel:03003000045)



Eyes are important, are yours being tested?

If you have had an eye screen test before, but not in the last 12 months, call: [0115 919 4411](tel:01159194411)

If you are not registered for eye screening yet contact your GP or practice nurse.



Feet need extra care when you have diabetes.

Speak to your GP/Practice nurse or other health care professionals when you have any concerns. They will make sure you get the right help.



Who can I expect to support me with my diabetes day to day?

- n GP
- n Practice Nurse

- n A range of healthy lifestyle services such as Healthy Change Call: [0345 604 7352](tel:03456047352)
- n Your GP may also refer you to the Community Dietitian



Your GP/Practice Nurse can refer you to a **Specialist Clinic** when more support is needed (see back page for areas). The clinics have a range of staff to ensure you get the help you need.

- n Consultant
- n Diabetes Specialist Nurse
- n Diabetes Specialist Dietitian
- n Clinical Support Worker
- n Psychological therapies (talk in confidence about coping with your diabetes)

If it's more appropriate to be seen in your GP practice then this will be arranged for you.



It's good to talk!

Feeling anxious, down or stressed? It can help to talk to somebody about it. Contact one of the free services in confidence:

- n Insight Healthcare - [0300 555 5580](tel:03005555580)
- n Let's Talk - Wellbeing [0115 956 0888](tel:01159560888)
- n Trent PTS - [0115 896 3160](tel:01158963160)

If you would like to get involved with self-help groups call Selfhelp UK on [0115 911 1661](tel:01159111661)



You will be referred to the **hospital** when you need their extra support.

For example - if you have active foot problems, are pregnant or have kidney problems.

Appendix 4: Stakeholder Topic Guide



Public Sector Stakeholders

Note: begin by requesting verbal consent - this should be recorded a part of the interview for audit purposes.

What is your role, what is your organisation/service, and what are your responsibilities within that organisation/service?

Which diabetes or respiratory (LTC) community services are you involved in commissioning/delivering?

Are any of the services specifically for BAME/BME communities?

Is there a specific marketing/publicity strategy for the uptake of diabetes or respiratory community services targeted at BAME/BME people?

What do you think are the barriers to BAME/BME people with diabetes or respiratory conditions from taking up community services?

Prompts:

- The way services are designed and delivered
- Cultural competence of service providers
- Language barriers for patients
- Patients' health beliefs about their long-term condition(s)

Do staff receive cultural competence training, if yes, what does this entail and who delivers the training?

Which diabetes/respiratory community services, if any, have a good uptake by BAME/BME people?

What are the enabling factors for good uptake?

What are the differences, if any, in the uptake of diabetes/respiratory community services amongst different BAME/BME groups/communities? i.e. have some engaged well with provision compared to others?

Are you aware of any strategies used elsewhere to increase the take up of LTC services with BAME/BME communities?

Do you have any views about how we should recruit research participants who are/are not engaging with diabetes or respiratory conditions community services?

Any lessons/good practice you would like to share?

Any other comments?

BAME community and faith organisations and faith groups

Note: begin by requesting verbal consent - this should be recorded a part of the interview for audit purposes.

What is your role, what is your organisation/service, and what are your responsibilities within that organisation/service?

Do you/your organisation work with specific BAME/BME groups? If so which ones?

From your perspective, how aware do you think members of the BAME/BME community are about diabetes and respiratory conditions?

What awareness do you have of BAME/BME diabetes or respiratory conditions community services in Nottingham?

How, if at all, have you supported the delivery of these LTC community services locally?

What are the barriers to BAME/BME people with diabetes or respiratory conditions taking up community services?

Prompts:

- The way services are designed and delivered
- Cultural competence of service providers
- Language barriers for patients
- Patients' health beliefs about their long-term condition(s).

What are the enabling factors for the uptake of diabetes or respiratory community services amongst BAME/BME people/groups?

Is there a need for a specific marketing/publicity strategy for the uptake of diabetes or respiratory services targeted at BAME/BME people? What might that involve?

Are you aware of any strategies used either in Nottingham, your community or elsewhere that have successfully increased the take up of diabetes or respiratory services?

Do you have any views about how we should recruit research participants who are/are not engaging with diabetes or respiratory conditions services?

Any lessons/good practice that you would like to share?

Any other comments?

Appendix 5: Participant Topic Guide



Increasing the uptake of primary and community long-term conditions services in Black, Asian and Minority Ethnic (BAME) communities in Nottingham City

Participant Topic Guide

Before beginning the interview:

- go through the Information Sheet with the participant
- obtain written consent via consent form (participant and researcher copy)
- ask if participant consents to the interview being recorded

1. Participant's Background

1. Do you mind telling me your age?
2. Do you live alone or with anyone else?
3. What is your ethnicity/ethnic background?
[Prompt: 1st or 2nd generation?]
4. What is your nationality/national identity?
5. What is your main spoken language? Do you read and write in this language? Any other languages? *[Prompt: English]*
6. Do you have diabetes *[type 1 or type 2]* and/or a respiratory condition? *[Prompt: asthma, COPD]*
7. How long have you had this condition?
8. How does this condition impact on your life?
9. How do you manage this condition on a day-to-day basis? *[Prompt: Explore any difficulties]*
10. Which services do you use at the moment to help you manage this condition?
[Probe: do you use any health services or other services in the community? why do you use these services?]

11. Have you used any other services in the past to manage this condition? [*Probe: why did you stop using them?*]
12. Do you have any other health conditions [*Prompt: physical or mental, e.g. anxiety, depression. Explore the link between this and long-term condition*]
13. Do have any caring responsibilities for family members or close friends? If yes, do they have diabetes [*type 1 or type 2*] and/or a respiratory condition? [*Prompt: asthma, COPD*]. Would you be happy to answer questions about your role as a carer as well?

If yes, repeat questions 7-12 from the perspective of the person they care for. Do the same for subsequent questions if appropriate/time allows.

[Interviewer to read out: 'I'm now going to move on to ask you some questions about your awareness and understanding of your diabetes and/or respiratory condition']

2. Level of awareness and understanding

1. How much do you know about your condition?
2. What are the symptoms?
3. Tell us what you know about how to manage your condition?
4. Where did you learn about the symptoms and management of your condition? [*Prompt: your GP, self-help group, other community groups, other health professionals, health pamphlets, own research e.g. internet, friends/family, other figures in the community?*]

3. Language barriers, interpretation and translation services [if relevant]

1. Have you ever had difficulty speaking/reading/writing English which stopped you attending an appointment for your condition?
2. Were you offered help from an interpreter? If yes, what was your experience?
3. Were you offered health pamphlets in your main language? How easy was it to understand? How useful did you find this?
4. Do you receive letters [for appointments, referrals, results] in your main language? Do you understand the information?

4. Marketing/publicity strategies

1. How do you receive health information currently about your condition?
Show participant visual materials, i.e. health pamphlets, posters etc.
2. How easy/difficult is this information to understand? How could it be improved? [*Prompt: explain why*]
3. What would work best for you in terms of raising your awareness and understanding of your condition? [*Prompt: letters, health pamphlets, posters, outreach workers, local radio*]

5. Sources of Support

1. Which health professional(s), if any, do you see to manage your health condition?
2. Which health professional(s) do you feel is best placed to assist you with your health condition? *[Prompt: explain why...]*
3. What role, if any, do self-help groups play in helping you to manage your condition? *[Prompt: what role could they play?]*
4. How do your family and friends help you manage your condition? *[Prompt: could you be supported any better?]*
5. How much trust do you have in those who help you to manage your health condition? *[Prompt: explain why] _Probe why they don't trust certain groups*
 - health professionals
 - self-help groups
 - family and friends
6. Do you currently receive or feel you need any additional support to manage your condition? *[Prompt: to get out and about, social commitments, to access services, to attend appointments etc.]*

6. Cultural awareness/competency of healthcare professionals

1. How well do you feel that the healthcare professionals that you're in contact with for your condition understand your language, cultural, and religious needs?
2. Can you give me an example of when your needs could have been better understood?
3. Can you give me an example of when your needs were met really well?

7. Religious and cultural barriers

1. Does religion play a role in your day-to-day life?
2. [If relevant] How do your religious beliefs influence your views on your health? *[Prompt: e.g. fate]*
3. How do your cultural practices influence your health? *[Prompt: diet, lifestyle, commitments to others]*

8. Discrimination and socioeconomic status

1. Tell me about your work, caring, and family commitments. How do these impact on your ability to attend health appointments and use healthcare services?
2. How does your financial situation impact on your ability to:
 - travel to appointments?
 - purchase medication?

- purchase healthy food?
 - pay for the gym or other activities?
3. Have you ever had an experience where you feel you have been treated differently to other patients, based on your ethnicity? *[Prompt: How did this make you feel? How did the experience affect your uptake of health services afterwards?]*

9. Provision of services

1. How well do services meet your cultural needs? *[Prompt: women-only spaces, prayer facilities]*
2. How well do the times/locations of primary and community health services fit in with your daily routine and commitments?
3. Which services in the community best meet your health needs *[Prompt: why?]*
4. How important do you think it is for patients to have a say in how services are designed and run? *[Prompt: Do you feel like you have a say currently?]*

Thank respondent for their time and reassure confidentiality

Give incentive payment to respondent and ask them to sign receipt

Appendix 6: Participant Information Sheet



An exploratory research study - Increasing the uptake of primary and community long-term conditions services in Black and Minority Ethnic (BAME) communities in Nottingham City

Participant Information Form

The Nottingham City Clinical Commissioning Group (NCCCG) has commissioned the Centre for Regional Economic and Social Research (CRESR), working in partnership with the Centre for Health and Social Care Research (CHSCR) at Sheffield Hallam University, to undertake an exploratory research study into the uptake of primary and community long-term conditions services by BAME communities in Nottingham City.

To understand the barriers and enabling factors associated with the uptake of services, we would like to interview a range of Black, Asian and Minority Ethnic people from Nottingham city with diabetes, or respiratory conditions (such as, COPD or asthma) who have **accessed support services** for their condition through a GP or in the community. We would also like to speak to people who have these conditions but **have not accessed services** to support them.

Participation would be much appreciated. Responses to the interview will be **COMPLETELY CONFIDENTIAL AND ANONYMOUS**. Absolutely no details provided by the participant will be made available to anybody other than the research team.

Typically the interview **should last no longer than 45 minutes**. The interviews will be recorded and transcribed, subject to consent, so that the researchers can fully analyse the content. The information provided will be held securely by SHU and will be anonymised. Although individuals' views, comments and suggestions may be included in the final report their name or any other identifying information will not be used. Participants will each receive a £10 high street voucher as a thank you for taking part.

For any questions or further information about the study, please contact a member of the research team:

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