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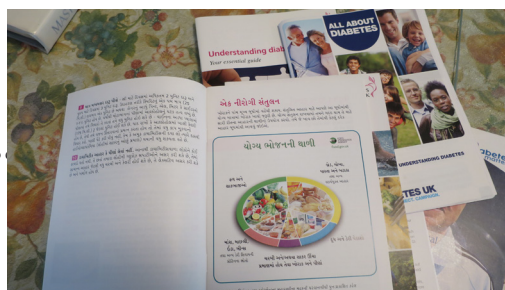
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AUTHORS
Hannah Wright
Dr Magda Buchczyk

Bromley Healthcare CIC

Understanding attitudes to
diabetes amongst the South Asian
communities of Thornton Heath



Contents

Contents	3
Foreword	5
Background & Objectives	6
Methodology	7
Introduction	10
Meet Mrs Ganjawala	12
Meet Mrs Jassar	13
Meet Mr Pathik	14
Meet Mrs and Mr Devar	15
There is a problematic attitude of inevitability around diabetes	16
Cultural and religious obligations act as barriers to lifestyle change, particularly when it comes to food and physical activity	18
Once diagnosed, effective self-management is inhibited by confusion and distrust	22
Healthcare providers must acknowledge the opportunity for change	25
Next steps	27
Appendix 1	28
Appendix 2	28
Appendix 3	28
Selected references:	30

Foreword

Type 2 Diabetes continues to be a high profile condition, and one that is forecast to become even more widespread in the future. Statistics show that the number of cases of diabetes has risen by 65% in the past 10 years¹, presenting an alarming challenge for the NHS, healthcare providers, patients and the general public.

Diabetes can have a huge effect on the quality of peoples' life, from changes in diet and lifestyle, to medication and regular monitoring of blood sugar levels. Patients are at risk of potentially developing complications including reduced vision, difficulties with mobility, kidney disease and amputations

The South Asian population in the UK is more likely to be diagnosed with diabetes, due to a variety of genetic and cultural factors. Whilst much needs to be done across the board to better understand the lives of those living with diabetes, and their wider contexts so that both treatment and prevention systems can be designed to halt the seemingly constant upward spiral of new diagnoses in the future, there is also a need to focus on specific communities who are most likely to be affected.

This research by ESRO has drawn on first hand testimony throughout, reflecting the realities of living with diabetes and some of the myths that surround the condition and its treatment. It represents a great opportunity for all those involved in healthcare provision to consider changing their interaction with a diverse range of communities and better consolidate existing work and progress in this area.

I would like to thank the ESRO research team for their enthusiasm and dedication in completing this research, alongside all of those experts and healthcare professionals who offered their expertise and experience to the team. Most importantly, we would like to thank all of the organisations who welcomed our researchers and the individuals who shared their experiences of living with diabetes. The work would be nothing without your input.

Jonathan Lewis
Chief Executive
Bromley Healthcare CIC

*We refer to 'diabetes' throughout, meaning Type 2 Diabetes

*All errors are the authors' own

Background & Objectives

According to recent figures from the Croydon Clinical Commissioning Group, there are **disproportionately high diabetes diagnosis rates** in the local **South Asian community** – with a large number of people also going undiagnosed.

However, this bias is **not currently reflected** in the provision of **information and education** regarding diabetes, with relatively little done to make such materials **accessible and culturally relevant** to the South Asian population.

Given this disparity, work was needed to engage the South Asian community and positively change behaviour with a view to:

- Preventing pre-diabetes escalating into Type 2 diabetes
- Better enabling the ongoing self-management of those who have Type 2 diabetes
- Reducing the number of health complications arising as a direct or indirect result of Type 2 diabetes

By achieving these outcomes, the **health and wellbeing** of the South Asian community in Croydon will be improved, and the burden placed on secondary healthcare services reduced in turn.

Bromley Healthcare has secured £50,000 of funding from the Health Innovation Network to conduct a **research-led innovation process** – bringing together expert knowledge, primary research and co-design to develop education and information programmes on diabetes that effectively target Croydon's South Asian population.

To inform and inspire this process, Bromley Healthcare required a research partner to provide **innovation-friendly insight**, and actively work with clinicians and other stakeholders to **translate insight into action**.

RESEARCH OBJECTIVES

ESRO was commissioned by Bromley Healthcare CIC to conduct research into the South Asian community in Thornton Heath, Croydon, with a view to answering the following specific research objectives:

- How people in the community manage their health in general – including health-specific information-seeking behaviours and preferences (e.g. tone, channels, barriers)
- The experiences, understanding, behaviours and attitudes of those managing Type 2 diabetes (e.g. routines, stigma, advice-seeking behaviours, use or non-use of digital technologies, consideration of possibility of future health complications)
- Underlying social and cultural factors that shape attitudes towards diabetes (and its causes)
- Effectiveness of different communications channels and local community assets in providing a range of education and information to the community

The overall objective of this piece of research was to provide an up-to-date and independent evidence base outlining the experiences and needs of South Asian communities in relation to preventing and managing diabetes and accessing a range of services and support. More specifically, the research sought to:

- Explore the needs of the local community - reinforcing/challenging data gathered during the knowledge audit, and identifying new opportunities
- Ensure the voice and perspective of the local community is at the heart of the innovation and design process
- Ensure the design is anchored to insight regarding the needs and barriers of the local community
- Develop understanding of the range and diversity of the population – ensuring that the service takes into account a full range of needs, rather than relying on stereotypes/assumptions
- Identify resources (through asset mapping) which may be able to support, shape and help deliver potential services – ensuring that the new services aren't designed to operate in a vacuum

Methodology

Our methodology included a strong emphasis on community structures and ethnography, in addition to a thorough knowledge audit.

In order to answer the research objectives, the below research methodology was adopted.

- **Literature review**

A literature review was conducted focusing on sources in medical and healthcare journals, academic publications in social sciences, psychology, community studies as well as self-help books. The review encompassed published and web-based reports, journal articles, books and booklets (see References).

- **19 x expert interviews**

These interviews were conducted with leading academics, clinicians, community representatives, diabetic nurses, local stakeholders, health organisations and charity experts (Appendix 1). The interviews focused on the experts' understanding of the context of work with South Asian communities in diabetes prevention, treatment and management and previous interventions addressing the issue (Appendix 2).

- **6 x days of ethnographic fieldwork in Thornton Heath**

The first phase of the research was ethnographic fieldwork in Thornton Heath. The aim of the ethnographic study was to elicit rich, detailed data on the existing social networks and community structures across all local South Asian communities, as well as examining their relationships with the locality at large.

On an individual level, ethnographic approaches involve the researcher, or research team immersing themselves within the community over a period of time and grasping 'the native's point of view' on health services, exploring the complexity of thoughts, beliefs, everyday actions and interactions between members of community and the health professionals. Such perspective allows to go beyond what people say they do to what people actually do in order to investigate health behaviours and specific barriers to engagement with public health interventions and healthcare.

Through attending informal group discussions and conversations with respondents across multiple sites, the researchers explored the "flesh and blood" of the local assets and potential influencers within the local community (e.g. faith groups, exercise clubs, diabetes support groups, religious celebrations, community meetings and open days). See Appendix 3.

- **6 x depth interviews (of approximately 2 hours in length)**

Local diabetes sufferers were recruited from a range of ethnic backgrounds to take part in an in-depth interview in their home. A range of gender, age, socio-economic background and ethnic background were recruited.

- 3 x Indian (Gujarati)
- 1 x Pakistani
- 2 x Tamil

The qualitative nature of this research allowed for a deeper exploration of the factors influencing the challenges of diabetes self-management in the South Asian communities. Individuals were asked more about their diabetes journey from diagnosis to present day, their experience within the healthcare system, attitudes to and experiences of self-management. Further questions covered lifestyle, typical decision-making, sources of inspiration, influence and motivations to change behaviour.

Note:

Throughout the report, verbatim quotes from the community ethnography and depth interviews have been included to illustrate certain viewpoints, particularly where there was broad agreement about an issue. It is important to remember that the views expressed do not always represent those of all participants.





Fig. 1: Mapping community assets in Thornton Heath

CATEGORIES



1. COMMUNITY

THE ARCHBISHOP LANFRANC ACADEMY
www.lanfranc.org.uk
 THORNTON HEATH LIBRARY
www.croydonlibraries.com/find-your-library/thornton-heath-library/
 THORNTON HEATH LEISURE CENTRE
www.fusion-lifestyle.com/centres/Thornton_Heath_Leisure_Centre
 UNMAH SPORTS
www.ummahsports.net
 SALVATION ARMY
www.salvationarmy.ie/thornton-heath
 WINTERBOURNE YOUTH CENTRE
 MUMS THE CHEF
 CROYDON BME FORUM
www.cbmeforum.org
 BROADGATE LIBRARY
 CRYSTAL PALACE FOOTBALL CLUB
www.cafc.co.uk
 BANGLADESH WELFARE ASSOCIATION
www.bwelfare.org.uk
 TAMIL WELFARE ASSOCIATION
 WEST THORNTON COMMUNITY CENTRE
www.westthornton.org



2. HEALTH

PARCHMORE MEDICAL CENTRE
www.parchmoremedicalcentre.co.uk
 LEANDER ROAD SURGERY
www.leanderfamilypractice.co.uk
 CAVENDISH HOUSE PRACTICE
 CROYDON UNIVERSITY HOSPITAL
 Medical Centre??
 MAYDAY PHARMACY
 SHIVAS PHARMACY



3. RELIGION

OSHWAL MAHANJAWADI JAIN TEMPLE
www.oshwal.co.uk/oshwal-centres
 SWAMI VIVEKANDANDA CENTRE
 CROYDON MOSQUE & ISLAMIC CENTRE
www.croydonmosque.com
 SHREE SAKTHY GHANAPATHY TEMPLE
www.ghanapathy.co.uk
 PARCHMORE METHODIST CHURCH
 - SATSUNG MANDAL
www.parchmore.org
 NORBURY ISLAMIC ACADEMY
 AND ISLAMIC CENTRE
www.norbury.org
 CROYDON GURDWARA
www.croydongurdwara.co.uk



4. FOOD OUTLETS

DEEPAK FOOD
 SAPNA CASH AND CARRY
 TANDOORI CORNER
 HALAL BUTCHERS
 KRISHNA NEWS
 SHOP RIGHT SUPERMARKET
 ZAINAB BOOKSHOP
 SANKALP SWEETS



5. ALTERNATIVE REMEDIES

ACU-HERBS
 KERELA AYURVEDA

Introduction

Thornton Heath has the one of the largest proportions of BAME, and more specifically South Asian, residents in Croydon (fig. 3).

Levels of Type 2 Diabetes diagnoses are higher than average amongst South Asian communities, not only in Thornton Heath but across the UK, due to a variety of genetic and lifestyle factors. Such a pattern creates a challenge for local health providers around targeting particular communities with relevant information and awareness campaigns, as well as treatment and self-management for those already diagnosed.

However, a further challenge lies in the wider community engagement strategy adopted by local healthcare providers. There are a number of barriers to engagement present with the South Asian community as a whole, including language difficulties, alternative healthcare providers, a lack of trust, and strong cultural and religious obligations.

To address the challenge on a local level, the decision was taken to focus this study on a specific geographical area in order to explore in depth the factors affecting diabetes prevention and management in the community.

Our research was designed to understand the communities themselves, as well as factors affecting diabetes prevention and management. Recognising the challenges of researching South Asian populations, due to cultural, communication and comprehension difficulties, we adopted a multi-layered approach to the fieldwork process which included an emphasis on community organisations. We visited locations where South Asian people gather to shop, pray, socialise, work and get medical advice and treatment.

THE COMMUNITIES

There is not one single homogeneous South Asian community in Thornton Heath, but rather a diversity of communities both united and divided by nationality (fig. 4), language, ethnicity and religion. They are further divided by socio-economic factors, and by length of time in the UK, with some communities well established, and others recently arrived.

There is often a tendency to talk of a South Asian ‘community’, and to focus on those features of such a community which are different to the wider population of the UK. However, this study sought to understand not only the factors, attitudes and challenges which potentially affect many members of a wider South Asian community, but the internal diversity and difference of such a group, and to what extent difference is a factor in health opportunities and outcomes.

A number of cultural, socioeconomic and religious differences were identified between the different South Asian communities of Thornton Heath, all of which significantly affect approaches to healthcare, attitudes to Western medicine and everyday behaviours related to diabetes prevention and self-management.

Rather than cohesive wholes, these subgroups tend to lead parallel lives within the wider community. We found that some South Asian communities, such as Gujaratis, consider themselves to be well established in the local area and see other, more recent arrivals, such as Tamils, as ‘newcomers’, with little understanding of life in the UK. Such newer populations face many challenges, not least practical language barriers and a greater likelihood of poverty, but also a lack of community structures and organisations within.

Single men, who have come to the UK for employment opportunities, were universally felt to be the most susceptible to poverty and isolation, often existing outside of any community structures upon arrival. When discussing healthcare attitudes and opportunities, there is perhaps more that divides than unites a first generation single male from Sri Lanka from an elderly Gujarati couple who have been living in the UK for 50 years, with children and grandchildren born in this country. Ethnic communities may keep strict boundaries in some areas of life while sharing others, and our research therefore explored a range of community assets that implied exclusive membership and others that served as regular touchpoints between various residents of the area.

Community assets include a very large number of people, organisations and ‘things’ - spanning both physical and social infrastructures, local amenities, businesses, faith organisations, political or interest groups or highly attended corner shops. These and other local assets play a crucial part in the everyday lifestyles of South Asian residents in Thornton Heath.

FIG. 3 DISTRIBUTION OF ASIAN AND BRITISH ASIAN POPULATION IN THE CROYDON BOROUGH

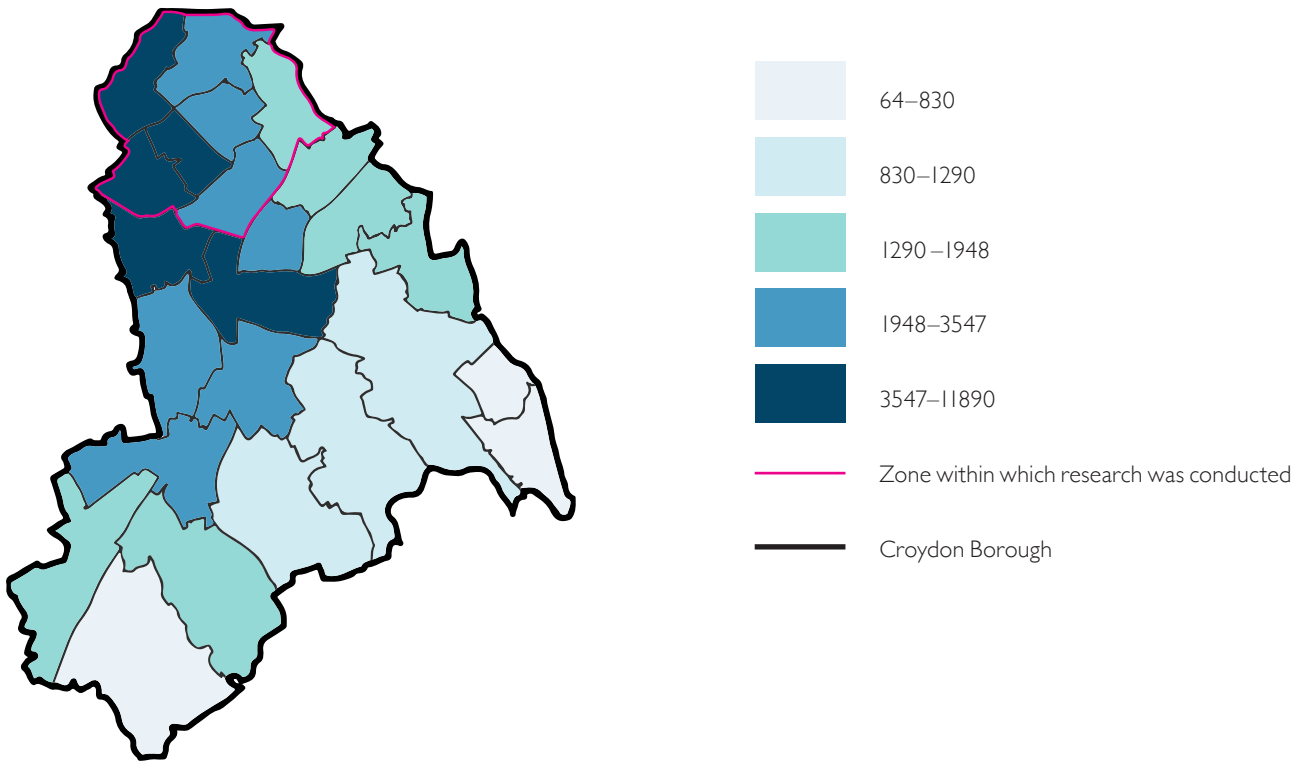
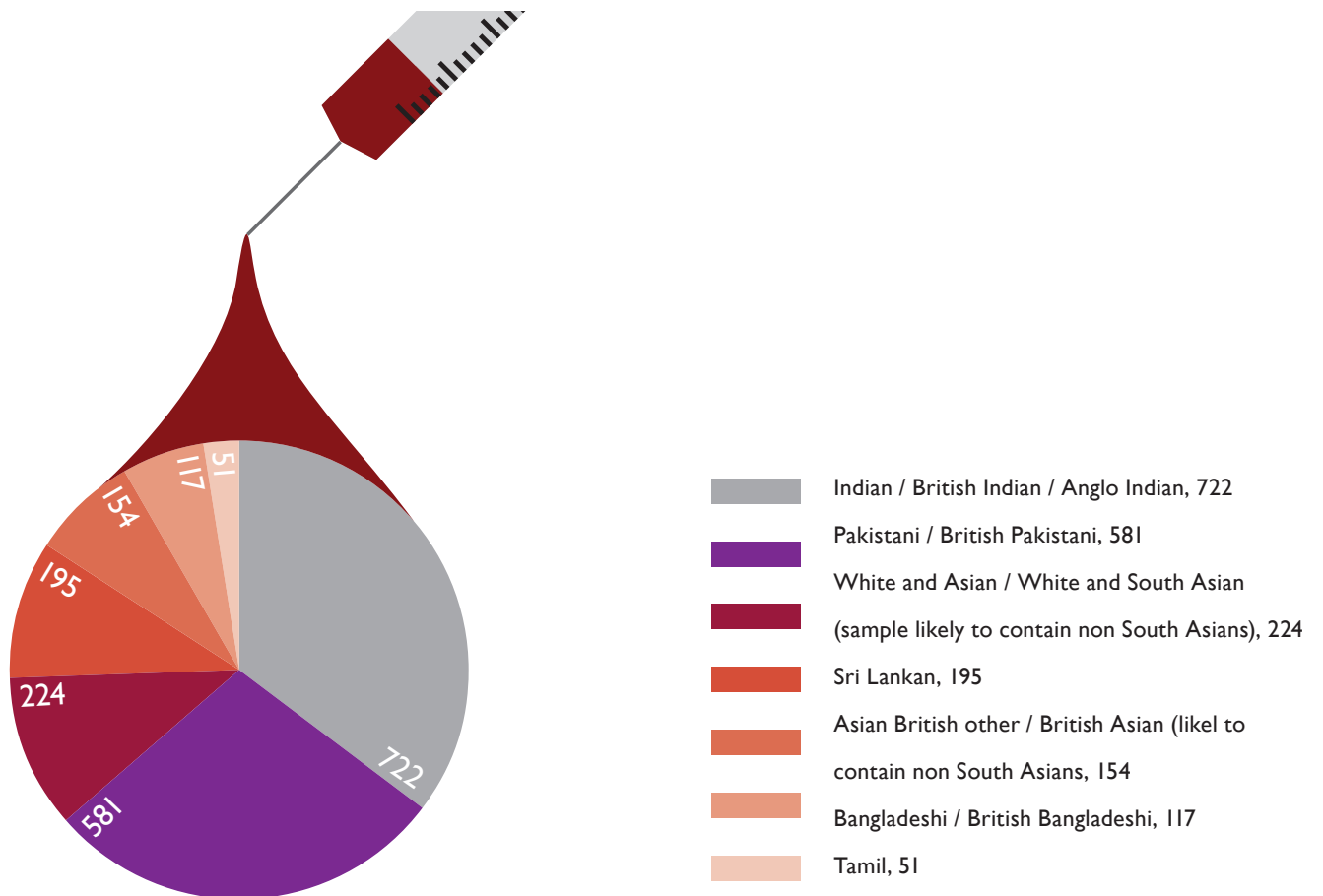


FIG. 4 SOUTH ASIAN COMMUNITIES IN THORNTON HEATH



Meet Mrs Ganjawala

Profile:

Age: 70-75

Background: India

Household: 2

Diagnosis: Diabetes Type 2



Mrs Ganjawara (70) is a retiree who enjoys taking part in community events. She is very sociable and attends several community events on weekly basis. She goes to the local Hindu temple twice a week and participates in a local organisation, meeting other women from her part of India.



DIET:VEGETARIAN

She places great emphasis on hospitality and has a reputation of being an excellent cook. On a daily basis, she prepares food from scratch, buying ingredients in one of the local Asian shops. With years of experience, she cooks intuitively and does not use any recipes or measurements. Cooking fresh, traditional food for her grandchildren is one of the greatest pleasures. For her, traditional vegetarian home-made food is a passport to health.

Being diagnosed with diabetes has not resulted with major changes to her cooking habits. When diagnosed, she has been given cooking leaflets which she doesn't believe are relevant for her diet. In her view, not only are the leaflets created for meat eaters but also following these recipes would result in "bland meals". Despite regularly seeing a diabetes nurse, she does not grasp the dietary advice given. Without a full understanding of the Western nutritional groups, she associates her diabetes with sweet sugars rather than carbohydrates.

"I can't eat sweet potatoes - I use potatoes instead"

She respects the advice of her GP and diabetes nurse and reduces her intake of sweets. One of the greatest challenges is related to keeping track of food intake. Products sold in the shops do not have labels with nutritional values and these figures are not clearly understood. As a traditional and intuitive cook she does not use any form of measurement.



HEALTH

Medicine: Prescription drugs and herbal remedies

She likes her doctor and takes recommended medication. At the same time, she uses a range of herbal remedies such as Ayurvedic tablets (shipped from India) and home-made plant based treatments. Although her GP disapproved of these methods, she continues to use them and trusts traditional treatment methods more than their Western counterparts. Her approach to health and wellbeing is embedded in a fatalistic attitude

"I just think - what can I do? Sickness happens."



FITNESS AND LIFESTYLE

Exercise: Yoga

Mrs Ganjawala believes that getting plenty of rest is very important for healthy living for elderly women. She prioritises this over exercise when describing a 'healthy lifestyle'. Occasionally, she does a combination of yoga and gentle exercise, with a local community group.

Meet Mrs Jassar

Profile:

Age: 55-60

Background: Pakistan

Household: 5

Diagnosis: Diabetes Type 2



Mrs Jassar is a Pakistani single mother living in Croydon with 4 children. As a result of an arranged marriage, she moved to the UK to join her husband in 1988. The move was a culture shock – she still remembers the moment when she first entered the small house with a tiny bathroom.

She felt that she familiarised herself with the UK after the birth of her 1st child when for many years, she shared accommodation with her mother-in-law who was the main decision maker about family meals. Her life changed significantly a few years ago when both her mother-in-law and her husband passed away. As children were still at school and she had to *“work everything out”*.



HEALTH

Medicine: Natural remedies

She recognises the importance of good health.

“I have to take care of myself for my kids. It’s my responsibility”

She feels that the stress associated with living alone contributed to her diabetes. In 2009, she was hospitalised with Hepatitis C and gallbladder stones. During a routine test, she was also informed she had diabetes. This came as a shock – she never had any evident symptoms – she didn’t feel anything. She regularly sees a Kenyan GP for her diabetes but finds thinking about it very stressful. She used to worry about it but currently, she prefers to carry on and live normally. She refuses to use prescription drugs but uses natural remedies - aloe vera juice, herbal capsules, bitter liquid, fenugreek seed, okra and Triphala Churna.



FITNESS AND LIFESTYLE

When she was diagnosed with diabetes she was told to do exercise. In her interpretation, housework provided a good replacement for formal fitness activities. She thought that she was sufficiently active doing housework and taking care of her children.

“I didn’t sit down until my work was finished”

Recently, she developed foot and back problems that slowed her down on a daily basis. This had become a serious barrier to exercise – she feels that she is getting weaker and needs to take multiple breaks while cooking or cleaning.



DIET

Diet: Religious restrictions

She finds thinking about diabetes very stressful. She knows she should be strictly dieting but likes to enjoy herself.

“You can control it yourself – the doctor said if you can keep control this way it’s ok”

The preferences of her children have a great influence on what she eats – her older daughter doesn’t like curries or chapattis, children try to convince her that healthy food is easier to prepare. Increasingly, they buy cookbooks, watch food programmes together and experiment with TV chefs’ recipes. She admits to having a sweet tooth and occasionally has cravings for Asian sweets. Contrary to health advice received at the mosque, she continues to fast during Ramadan. She uses supplements to support her during the fast and has a healthy evening meal. On a regular basis, she also tries to keep a weekly fast.

Meet Mr Pathik

Profile:

Age: 80-85

Background: India

Household: 2

Diagnosis: Diabetes Type 2



Mr Pathik is 84 years old and lives with his wife in the Croydon area. He was born in India, lived for a while in Kenya and came to the UK in 1977. Trained as an accountant, he speaks Gujarati, Hindi, Swahili and English. On arrival in London, he started his own business and owned a small shop until he retired a few years ago.



HEALTH

- Exercise: Walking
- Medication: Insulin

Mr Pathik was diagnosed with diabetes in the 1980s. He regularly sees his Indian GP and diabetic nurse and attends the local Diabetes UK roadshows. At the outset of his condition, he was on diet control and took prescribed medication. In 2001, he started to take insulin injections and in hindsight, he didn't find the change difficult.

"In fact, insulin is better than going on medication. Diabetes well controlled"

"In the beginning you feel it but once you start taking it, there is nothing to worry about"

He used to act as a volunteer interpreter for his Indian friends but is unsure if translation is an answer to communication with healthcare

"I remember that one day DIABETES UK had a display of diabetic material. It was in a temple, they got in about a thousand leaflets all printed in Gujarati. Hardly any of them were given away but the rest, they left the temple and just threw them away. I went to collect them"



FITNESS AND LIFESTYLE

Mr Pathik had a very busy and active life. On retirement, he decided to slow down and does not tend to do intensive exercise. He personally does not like organised activity like yoga but enjoys walking. He leads a rich social life, visiting several temples and community centres over the week.

"I do go to Indian organisations and community centres for prayers and to have something to eat, some snacks"



DIET

- Vegetarian

He has a strong preference for traditional Indian diet. He likes home-cooking and most meals are made from scratch by his wife. In addition, he attends several community luncheon clubs. He never counted calories or carbohydrates but occasionally tends to fast.

'Indian diet a healthy diet, not junk good you know'

Meet Mrs and Mr Devar

Profile:

Age: 45-50

Background: Sri Lanka

Household: 6

Diagnosis: Diabetes Type 2



Mr and Mrs Devar are a couple of Sri Lankan refugees living in Thornton Heath. As a low income family with four children, their greatest priority is making ends meet and educating their children. Mr Devar works in a factory, his wife is currently unemployed.

“There is no opportunity to think about health. Every day we think about work and money. Wealthy people don’t worry about these things, so they can think about health and exercise.”



HEALTH

A few years ago, Mrs Devar had a stroke that affected her health and mental wellbeing. Since then she has problems with her manual dexterity, sight and coordination and suffers from anxiety. They both have diabetes and regularly visit a local GP. They have been given information related to the stroke recovery, including recommendation on specific exercise which the wife follows. At the same time, no advice on diabetes is considered as a priority. In contrast to the stroke, diabetes has no alarming symptoms. They have a good relationship with their GP although find it challenging to arrange appointments around busy family schedule. They rarely read information leaflets provided by their doctor and sometimes skip the prescribed medication, arguing that they have no time to read or remember. Both their GP and diabetes nurse speak Tamil – they find it very useful as the wife does not speak English.

“She is very knowledgeable about diabetes. She told us, do exercise, reduce rice, use the tablets – the usual thing.”

Mrs Devar feels that stress and the trauma of civil war were major factors contributing to the development of their diabetes.

“When I was younger, I didn’t know about diabetes, but after the conflict, the bombs, the war, its diabetes diabetes everywhere.” “All the stress I think is why the people with diabetes increased.”



DIET

The Devar family finds following a traditional diet a very important part of their identity. Since his wife’s stroke, the husband took over some of the cooking responsibilities. On a daily basis, they cook from memory, occasionally use a Tamil recipe book in Tamil and shop for Sri Lankan food in local Asian shops. The younger children prefer Western and fast food. They haven’t changed their diet much since being diagnosed, however they are able to parrot the dietary guidelines: less rice, less sugar and less salt, more spinach and green vegetables. They feel that thinking too much about dietary adjustments is difficult. They would rather not be given information as it would force them to think about it. More stress can worsen the symptoms of diabetes.

“I don’t want to learn about it, because then I’ll start to worry about it, which will make it worse.”



FITNESS AND LIFESTYLE

- Exercise: Stroke recovery manual exercise

With limited resources and busy family schedule, it is challenging to find time to socialise and exercise. Mrs Devar goes on occasional walks with her teenage son but is frail and anxious about going out on her own. She does stroke recovery dexterity exercises prescribed by her doctor. Mr Devar works up to 14 hours a day and is too tired to exercise.

There is a problematic attitude of inevitability around diabetes

Although diabetes is part of everyday conversations, there is a lack of knowledge about the condition and a culture of denial surrounding the causes. This negates personal responsibility for the condition and prevents behaviour change

DIABETES IS SEEN AS 'NORMAL'

The study found that diabetes is an integral part of everyday life for the older South Asian residents of Thornton Heath.

Throughout our ethnographic fieldwork, including organised discussions and ad hoc conversations, we found that almost everyone spoken to had some experience of diabetes, either directly, or indirectly through friends and family.

We were surprised to note the candour with which residents informed us of their diagnoses, having expected a degree of shame or embarrassment around the condition. On the contrary, diabetes appeared as a normalised, routine experience for elderly South Asians. Such an attitude bodes well for future healthcare engagement around the issue of diabetes, with no barriers to discussion observed during our research.

However, despite such a willingness to talk about diabetes, and acknowledgement of the widespread nature of the condition amongst South Asian communities, over the course of several conversations with local healthcare in Thornton Heath and through our own conversations with patients it became clear that many have a poor general understanding of the symptoms and the causes of the condition. Many were felt to deny or ignore early warning signs, and there was little sense of the importance of preventative or precautionary measures.

"Especially the older generation they leave it until it happens, there is no precautions" (Mosque leader)

Often, those at risk fail to recognise, or are simply unaware of, the symptoms of diabetes. A local pharmacist involved in the research had identified a number of patients through their attempts to buy over the counter non-prescription drugs for eye or foot conditions.

Beyond a simplistic understanding that diabetes is caused by "sugar", there was little knowledge of the condition itself, and the numerous causes. Such misunderstandings compounded an already strong sense of inevitability around the condition. Many of those spoken to as part of this research saw a diabetes diagnosis as another symptom of old age, and an inevitable condition for people their age. There was little discussion or acknowledgement of the impact of lifestyle factors on a diagnosis, and it was felt that little could be done to stop it.

A CULTURE OF DENIAL

Causes of diabetes were frequently externalised and patients often cited a number of factors outside their control as the reason behind their condition. There was a sense that illness was beyond an individual's control, particularly long-term conditions in old age.

"What can I do? Sickness happens" (Mrs Patel)

In a comparative study, Grace et al. (2008) found that South Asians more likely to externalise responsibility of diabetes, reporting general life circumstances as central to cause in comparison with internalised responsibility by other groups.

There was a strong sense of hereditary determinism and family connections when it came to diabetes, with several participants describing their inability to control such an outcome. Diabetes was seen as particularly common amongst South Asian communities, something which added to the sense of inevitability around the condition.

"If you haven't got diabetes, you probably aren't Asian!" (Shopkeeper)

For some, diabetes, alongside other illnesses, was simply God's will, rather than the result of particular lifestyle choices, a finding mirrored by Lawton et al (2006) who reported that first-generation

respondents regarded the development of diabetes almost universally to factors outside their control, including the will of God.

In addition to seeming inevitable, diabetes was often seen to be “caused” by the experience of the change of climate brought about by migration to the UK. Colder weather was blamed for the increasing prevalence of the condition, as well as the stress of life in the UK. On several occasions, the root of a diabetes diagnosis was seen as a direct consequence of moving to the UK, with its comparative lack of sun and outdoor activity. Cooler weather was blamed for a lack of sweat, which is seen as a key aid to digestion. In contrast, India, Pakistan, Bangladesh and Sri Lanka were seen as healthier places to live, with more sunshine and a more active, less stressful lifestyle.

“Here we don’t get sun. There are six months of winter, four months of rain, and no summer at all. If there is sun, you walk to go to places. But in the rain, you get a car and go”

For some, a stressful life in the UK was seen as a generic factor, due to a faster pace of life.

Others linked the condition to more specific instances of stress over the course of their lives. One Sri Lankan housewife blamed the epidemics of diabetes in her community on the trauma of armed conflict and war in Sri Lanka. Another Pakistani patient saw her diabetes as a result of a turbulent time at home.

Others associated diabetes with a ‘non-stop’ life and the responsibilities of work. For such patients, taking care of one’s health meant wasting valuable time at work or with the family, and we found some who regularly skipped GP visits or health checks due to their perceived drain on time

“I can’t afford hanging around in the morning... or all day” (Shopkeeper)

In this context, it is important to acknowledge the varied meanings of stress when cited as a key factor in diabetes diagnoses.

Across the board, we found little knowledge of the impact of lifestyle and behaviour on the likelihood of developing diabetes, and little acknowledgement of individual responsibility for any aspects of the condition. Whether it be a complete rejection of any responsibility for health, or an exaggeration of other contributing factors, there remains a lot of work to be done to educate the South Asian communities about the impact of lifestyle choices on health, not just in relation to diabetes, but other conditions too.

A TEMPORARY CONDITION

Across the board, there was some confusion around the permanency of diabetes, with certain patients approaching it as a temporary ailment to be ‘cured’, rather than a lifelong condition. This had knock-on effects in terms of lifestyle, diet and medication, as patients tended to forget good habits once they felt better. Such misconceptions about the temporary nature of diabetes led to periods of lack of self-management and medication holidays, when satisfactory blood sugar levels were achieved, or alternative medication available.

“A lot of people think it’s like fever. You take a tablet and you’re ok” (Shopkeeper)

Several South Asian communities in Thornton Heath engaged in fasting and feasting at particular times, primarily for religious festivals or rituals. Diabetes self-management was adjusted to fit these occasions, often against the advice of healthcare professionals. These religious and social rhythms were prioritised in various contexts including Muslim, Hindu and Buddhist populations.

“When I fasted during Ramadan I didn’t take my medication and it wasn’t a problem. I like to live a natural lifestyle” (Sri Lankan Muslim)

Although the local mosque leadership had been raising awareness of the possible risks associated with medical non-compliance during Ramadan, we found that some believers had continued to prioritise their religious duty over their diabetes self-management. Adherence to religious duties was often seen as more important, and valuable, than medical compliance.

“Follow the message and then you’ll discover that it’s good for you”

Muslim patients explained to the research team that, according to Quran, the body is a temple that requires regular fasting, a holistic physical and spiritual maintenance without Western medicine. Such beliefs are difficult to align with prescribed medication and lifestyle change for a lifelong condition such as diabetes.

During discussions with non-Muslim patients, too, the research team were told about the benefits of fasting, and a more holistic approach to medication and healthcare. Such practices and beliefs will be a major challenge for the healthcare profession when encouraging compliance with medication, and ensuring understanding of its worth amongst patients.

Cultural and religious obligations act as barriers to lifestyle change, particularly when it comes to food and physical activity

There are many aspects of everyday life in South Asian communities in Thornton Heath that exacerbate the causes and symptoms of diabetes

CULINARY HABITS ARE DEEPLY INGRAINED IN COMMUNITIES

Food often plays an important role in community, tradition and family life, and South Asian communities are no exception. South Asian cuisines encompass a rich range of culinary practices from veganism, through multiple cuisines of Indian regions to Pakistani food with strong Middle Eastern influences. All these traditions can be found in the homes and take-away restaurants of Thornton Heath.

Among South Asian communities, food is central to maintaining cultural connections with the homeland but also building relationships within the family and the wider community. Food is a form of communication, reciprocity and hospitality; connecting communities and embodying shared beliefs, practices and values.

Numerous studies of several South Asian communities have demonstrated that food-related community values can pose a significant challenges to effective diabetes self-management. Khunti et al (2009) suggested that even after diagnosis, people continue to eat traditional cuisine as they do not want to isolate themselves from their community.

Throughout our research we found that for most respondents, home cooking was central to culture, and traditional methods overruled healthier recipes given by nutritionists or other professionals. Recipes had often been passed down by family members, and were therefore of sentimental value to many. Few used the word 'recipe', however, to describe their cooking practices; there was a sense that recipes were required for dishes you were unfamiliar with, rather than family staples.

In the majority of South Asian households, eating habits were determined by women who cooked for the entire family. Their choice of food and cooking methods was often influenced by other family members; pleasing children, husbands and parents is a central part of a woman's role as carer. It will be crucial when assessing the messaging delivered to South Asian communities around food that the influence of other family members is taken into consideration. Over the course of many conversations with women who cooked for others, we found that many were unwilling to change well-loved dishes or methods of preparation due to their own diagnosis.

Despite health warnings, Khunti et al (2011) and Johnson et al (2011) found that many South Asians believe in preparing the best food for family and friends, often rich in fat and carbohydrates. Their research found that these meals are usually prepared by women, who even after a diagnosis of diabetes, might not change the way they cook and eat so that they continue to please family and friends and, in so doing, remain a valued member of the community. Our research mirrored such findings, with many older female patients expressing concern at the effects of altering or adapting recipes to make them healthier on others' enjoyment of the food.

"The balance is with the ladies, they hold the upper hand over cooking" (Mosque attendee)

Alongside home-cooking there was a marked appreciation of take-away foods. These were perceived as special treats and in many cases formed part of the weekly family diet, perhaps at the weekend or for a special occasion. Children were usually described as the instigators of such habits, regularly asking for Western style 'fast-food' such as pizza, chips or fried chicken.

When not eating traditional South Asian food, then, families are indulging in high fat, low nutritional food with higher than recommended levels of salt and sugar.

Single men, without family responsibilities and someone to prepare their food for them often ate the majority of their meals at take-away restaurants, however usually of the South Asian variety, seeing such food as a cheap and sociable way to maintain a traditional diet.

Taste and quality were constantly noted as crucial considerations. Grace et al. (2008) found that, for their study participants, changes to traditional recipes could not be made without having to choose less appealing, “bland” and “unpalatable” Western food. Social and cultural expectations were highly valued and certain standards of food preparation were expected to please both family and guests. In addition, traditional recipes and methods were universally thought to bring better taste, and were often closely associated with family members or relatives. Those who prepared food were often reluctant to change their habits, seeing any change as an acceptance that their previous technique had been flawed in some way. Understandably, experienced cooks and those using recipes passed down through the generations were often unwilling to change their behaviours.

“I don’t like the sauce they say you should make in the diabetic book – that’s not how I make my sauce. I make mine the Indian way.” (Mrs Patel)

MANY PATIENTS STRUGGLE TO ENGAGE WITH ADVICE AROUND DIET

In keeping with the lack of understanding demonstrated around causes and symptoms of diabetes, we also found that many struggled to engage with the dietary and nutritional changes required of them post-diagnosis. A lack of clarity around causes meant that treatment and advice did not appear as logical and rational as it perhaps could have done.

When asking diabetes patients to radically change their diet and attitude to food, it must be clear the role food plays in the diagnosis of the condition, and will continue to play throughout.

We found that a large number of patients struggle to fully understand and engage with nutritional advice. Many had a simplistic understanding of sugar as the root cause of diabetes, but interpreted sugar literally, without an understanding of the role of carbohydrates, for example.

Patients often did not have clearly defined ideas of the extent of diabetes-related adjustments required, or where to start in terms of implementation. There were two forms of reaction to the diagnosis; a presumption that everything was off-limits and there is no longer anything they can eat, or a presumption that the advice does not relate to South Asian food.

“My brain was blocked – what do I eat now?” (Jasmin)

Many respondents felt that dietary advice was not tailored to their particular eating practices and alternatives were not fully explored during the initial consultation with a dietician or nutritionist. Many vegetarians found it particularly challenging to understand the intricacies of diet management with diabetes.

“They sent me to a dietician – all the dietician did was give me a list. At least half of the items on there were vegetarian – they were telling me to cut down on vegetarian food, but I don’t eat anything else. They were telling me not eat rice or chapattis but if I don’t eat rice or chapattis, I don’t fill my stomach”

As many did not have an understanding of Western food groups and classifications, such consultations can be confusing and complicated.

There was a widespread understanding that sugar must be reduced to effectively self-manage diabetes, but this was interpreted as a reason to stop drinking sugar in tea, for example, rather than implement a larger scale change to one’s diet.

“I don’t have any sugar in my morning tea, which is better.”

“I eat Kit Kats because they’re not very sweet”

Without a more comprehensive behaviour change, such small adjustments can lull patients into a false sense of security and prevent wider changes taking place.

Furthermore, in the majority of cases those preparing food were not using recipes or measurements of particular ingredients such as oil or ghee. There is therefore no tangible way of assessing dietary modifications in a standardised fashion; one person’s “little bit of oil” may be quite different to another’s.

Ingredients were for the most part purchased from local shops, and in many cases did not contain any indicators of nutritional values, as is now widely found in supermarkets across the country.

There is therefore very little to help those preparing food to become aware of the nutritional values of individual ingredients, or to systematise change in habits as a result of a diabetes diagnosis.

More systematic work is required to drive change beyond ‘quick wins’ such as unsweetened tea and a change in chocolate biscuit habits, alongside better exploration of an individual’s culinary habits at diagnosis, in order to best tailor nutritional advice to their specific needs and situation.

EXERCISE IS NOT SEEN AS 'SOUTH ASIAN'

Most South Asian respondents met in Thornton Heath would consider themselves as active and hard-working people who care for others and are constantly on the move. The research found that South Asian participants rarely considered physical fitness as a separate goal. Exercise and activity are seen as integral parts of daily life, not separate endeavours or leisure activities. Sport and fitness are not seen as typical 'South Asian' leisure activities. Activity is associated with being young, and also with life back home, where manual labour and walking long distances are more common.

For many of our respondents, being physically active was not perceived as high priority. The culture of a strong work ethic meant that men felt obligated to dedicate their time to working very long or antisocial hours. Women felt they were engaging in sufficient physical activity during housework, care for their families and daily activities.

"I do a lot in the house so I think I'm pretty active"

Exercise was seen as an abstract category and most respondents could not imagine themselves in an aerobics class or a gym. Most of those who were advised to be physically active, understood exercise as taking walks. Overall, we identified an absence of exercise culture.

As mentioned earlier, men prioritise work and socialising and rarely consider fitness as part of their leisure activities. For both genders, representation of exercise does not connote a separate, individually-driven, rewarding activity.

In particular, Greenhalgh et al (1998) paper explored a range of themes relevant to Thornton Heath. They highlighted significant misconceptions about resting and exercise. In some contexts, physical activity was considered as negatively impacting health or exacerbating illness by increasing physical weakness. There was no concept or goal of being physically fit or gaining enjoyment from exercise. In this context, it was difficult to make time for dedicated physical activity. For men the culture of a strong work ethic meant they felt obligated to dedicate their time to providing for their family working very long or antisocial hours often in shops or restaurants.

WOMEN'S 'ACTIVITY' IS IN THE HOME

In addition to the blurred image of what 'being active' means, we identified several practical barriers to exercise. As we learn from Mrs Jassar's example, diabetes is often one of many conditions. Specifically, older patients might have multi-morbidities, and often these can prevent or hinder a more active lifestyle. As diabetes is often a 'hidden' condition, those with more obvious or painful symptoms are prioritised by patients.

These findings on the practical and ideological challenges around physical activity were also examined in the literature. Lack of physical activity and exercise culture are major risk factors for diabetes development in South Asian communities (Khunti et al, 2009, Netto et al, 2007; Grace et al, 2008; Johnson et al, 2011, Rhodes et al. 2003, Stone et al. 2005). It was argued that low physical activity was linked to cultural norms, social expectations, time constraints and health problems. For example, women are expected to be active in their daily lives in the household rather than participating in organised activity (Sahf 2014).

Srisikantharajah and Kai (2007) observed that promoting physical activity among South Asian women may be particularly challenging. Their participation in exercise may be inhibited by avoidance of mixed-sex activity and fear of going out alone. We found that many women in particular were nervous about participating in exercise as certain types of activity do not correspond with social rules of modesty, grace and cultural representations of femininity.

Many Muslim women we spoke to were particularly concerned about modesty whilst exercising and saw little opportunity for appropriate exercise in a safe and secure environment. We also consulted several older women from other religious backgrounds who expressed a preference for doing physical activity with their peers, as they were uncomfortable with the presence of younger people, or of the opposite sex.

Srisikantharajah and Kai (2007) also found that some South Asian women may only value activity that is consistent with their perceived role as homemakers and as carers of children and other relatives. The notion of "exercise" for oneself may be perceived by some, especially by older women, as a "selfish" activity.

Our research pointed in a similar direction, with some women telling us they were engaging appropriately in physical activity through care-giving and housekeeping. Not only does this negate a need to do exercise, as there is a sense that life itself is active enough, but women were also prioritising their home life and duties over their physical fitness, preferring, or feeling they needed to, spend time at home with their family.

OPPORTUNITIES

- How can we make South Asians excited about a healthier diet?
 - Discussion of changing culinary habits is best placed if it comes from within communities themselves. Questions about technique, taste and ingredients are important, and should wherever possible be answered and addressed by trusted members of the various South Asian communities. This way, advice will be tailored to specific traditions, rather than imposed by others with little understanding of the importance of food and culinary tradition.
 - In addition to targeting food preparation, attention must be paid to what happens before. Discussion of shopping habits and ingredients bought could be a tactful mechanism for encouraging change, without being seen to criticise individual technique or recipes passed down through a family.
 - Involving culinary establishments could be an innovative way of diversifying messaging and communication within South Asian communities. It is crucial that healthcare providers take into consideration all the potential contact points they could have with diabetes patients, and the opportunities for presenting and reinforcing messaging around diabetes.
 - Change must come from others in the household, not just whoever is in charge of food preparation. Engaging children in the messages around diabetes and its effective prevention and self-management could ensure that women are better able to adapt recipes and eating habits for their families. In the same way, ensuring that partners and children are involved in understanding what a diabetes diagnosis means will help pave the way for change for the entire family.
- How can we make sure exercise isn't dismissed by South Asian patients?
 - More effective signposting on the part of healthcare providers to the services currently operating in communities would be an effective first step in addressing some of the barriers to physical activity discussed in this report. Engaging current initiatives, many of which were visited throughout this research, would be a positive step towards not only understanding current community attitudes and concerns, but also towards ensuring those who need support are aware of its existence.
 - That said, there is a need for expansion of current community schemes which cater for these communities. Supporting initiatives that have grown out of communities themselves could aid expansion and growth, enabling more people to get involved and reap the benefits of physical activity.
 - It is crucial that each community, and target audience within, is consulted on new schemes and initiatives. The best placed people to comment on ideas are those whom we would hope would attend. What is more, the very process of community consultation can prove to be engaging in its own right, alerting people to the need and importance of a condition like diabetes and the barriers surrounding physical activity.
 - As with food, working with children to establish early on the need for, and importance of, physical activity will not only lead to the potential for change at a family level, but also work to create lifestyle changes at a generational level. Such changes will be crucial for prevention of diabetes in the future.

Once diagnosed, effective self-management is inhibited by confusion and distrust

A preference for traditional medicine, coupled with a lack of understanding around Western medicines and healthcare systems, often results in patchy self-management

UNDERSTANDING THE SYSTEM

The UK healthcare system can sometimes represent a confusing picture for a number of South Asian residents of Thornton Heath, often those who are first generation immigrants, or the elderly. As shown through dietary advice examples, patients can be confused by information given and specifically, by the numbers of different people they come into contact within the healthcare system.

“The doctor will say: ‘why are you taking this medicine?’ – but I don’t know why I’m taking it – that’s why I just use one GP” (Current diabetes patient)

We have identified a significant link between healthcare and trust enabling social networks. Our respondents often had a preferred GP whose advice they trusted implicitly. Family or other community members who work in the healthcare system were seen as important sources of information, and their thoughts can often override more professional advice. Many would forgo appointments until they could see their preferred GP, or simply not attend their local practice but call upon friends and family for help. This tendency was also highlighted by Greenhalgh et al (1998), who pointed out the importance of family networks as main sources of information, primarily through word of mouth.

As we have seen, building relationships is vital to South Asian patients, but difficult within current timeframes for appointments. With 10-minute slots at the GP surgeries, many South Asian patients struggle to build relationships of trust that improve their relationship with healthcare and understanding of the condition.

CONCERNS AROUND MEDICATION

During discussions about current diabetes self-management, many respondents expressed fears and concerns around prescribed medicine. Often, this was the result of a lack of knowledge and understanding around the prescription, perhaps due to difficulties communicating with the GP, or conflicting sources of expertise and advice. In some circumstances patients preferred to obtain medicines from their country of origin, trusting them more. Again this could be due to the opportunity to discuss the medication in their mother tongue, or to be able to source an alternative medication. There were some suggestions that medication available outside of the UK was stronger, although nobody could provide us with specific types of medication to support this view.

Whatever the cause, a lack of trust around prescribed medicines ultimately leads to ineffective self-management. Patients who were unsure of their medication were less likely to stick to the prescribed dosage and frequency, often skipping tablets in favour of herbal remedies, or just not taking them at all.

We also found a lack of engagement with literature available on the subject of diabetes, both prevention and self-management. Nutritional or informative leaflets in a range of languages failed to engage patients, despite being talked about as a positive resource by healthcare professionals. Often it was felt that leaflets were handed out in place of a discussion with the healthcare professional, perhaps due to a lack of time in appointments or a communication difficulty. However leaflets are rarely read (a problem that does not exclusively affect the South Asian community) and topics, questions and problems can easily go undiscussed.

Some older women had difficulty reading their mother tongue, and were unable to engage with leaflets given to them by well-meaning professionals, but too embarrassed to explain this in an appointment setting. Others gave leaflets to trusted friends and family to explain, again opening up the opportunity for conflicting advice and expertise to crowd out a sometimes fairly simple message.

Ukads (2008) found a similar phenomenon, and suggested the role of link workers to be crucial, building a bridge between GP and patient that cannot be solved through the giving out of leaflets.

NATURAL REMEDIES ARE WIDELY TRUSTED

As life in South Asia is commonly perceived as healthier, more active and natural, some of those who visit their homelands often periodically discontinue their medical treatment.

On visiting several local shops, the research team encountered a range of alternative medications helping to restore the sugar levels in the body. Holy basil, bitter gourd (karela), bitter curry, neem leaves, fenugreek seeds and other remedies were commonly used as trusted medicine. There was also a number of Ayurvedic tablets available over the counter and additional remedies were brought from home by family members and friends.

Our research suggests that herbal remedies are used for diabetes. In addition to these pre-packaged products, we found a high proportion of diabetes patients making their own remedies at home, based on family recipes or advice from friends. These remedies were often credited with improving the condition. Many alternative methods had strong family connections, and were reminders of home, and loved ones.

In tandem with our field data, Pieroni et al (2008) demonstrated that Pakistani migrants have their own strategies within their households for counteracting diabetes, and that they use a number of traditional medicines.

INSULIN

This lack of trust was evident in relation to insulin, which is widely seen as the culprit of various serious complications – such as losing legs or feet. During the interview, one respondent confessed that fear of insulin prevented him from visiting his GP:

“I don't want to go to the doctor, because they've told me that if my blood sugar goes higher, I have to go on insulin”

One of the frequent misunderstandings among south Asian people is that insulin is used as a last resort. The local librarian told the research team that:

“Once you go on insulin, you know it will be for your whole life, and people are scared they won't be able to come off it”

Khunti et al (2011) identified a similar attitude to insulin associated with a downward spiral. Patients felt that once prescribed insulin, there was “no hope” of effectively managing the condition, and began to fear associated conditions, such as deteriorating eyesight, much more. Some of those we met associated insulin strongly with the loss of legs and feet, and were as such reluctant to consider the idea of it being a medication option for them.

Some respondents feared insulin because of was perceived as a medication with higher risk. One Gujarati respondent mentioned that he was concerned that by taking insulin he could mistakenly give himself an incorrect dose and ‘go into shock’. Horror stories circulate widely amongst family and peer support networks, and prevent engagement with medication at earlier stages of the condition.

OPPORTUNITIES

- How can we be sure patients are taking their medication properly, and understand it?
 - It is imperative that healthcare providers and professionals make use of community leaders, existing schemes and organisations to tackle misconceptions and myths around medication. Previous research, and current behaviours, are testament to the need for a new strategy around medication, and this will be better delivered through those organisations and individuals who are trusted. What is more, there are ample opportunities to engage with such cultural or religious organisations, as demonstrated by this research itself. Expert, professional advice is required, but it must be delivered through existing channels in order to be effective.
 - In addition, talking to South Asian patients fully and frankly about any concerns with medication or questions could mean that certain initial fears are identified and tackled head on. Such an approach could also extend to changing information, including leaflets, provided to patients. Tackling common myths and misconceptions in such literature or communications may help to bring such issues to the surface, where they may be better resolved.
 - Herbal remedies, their use and status, must be addressed by healthcare professionals. Ignoring or dismissing their use only serves to ensure that patients are not honest with their GPs or nurses about their usage. Encouraging patients to talk about their herbal remedies, and why they take them, will better equip healthcare professionals to prescribe medication and address any issues with it going forwards.

- Explaining the importance of prescribed medication may require an acceptance on the part of healthcare professionals to the usage of herbal remedies. Not being seen as 'anti' herbal remedies may encourage better adherence to medication which is prescribed, as patients do not feel they have to choose between the two. Furthermore, it may be that many patients are diligently taking herbal remedies, and this behaviour can be tapped into in order to improve behaviours around prescribed medication.

Healthcare providers must acknowledge the opportunity for change

KNOWLEDGE AND ADVICE

There is an incredibly wide variety of community, religious and social organisations operating within the various South Asian communities of Thornton Heath. Residents were found to have wide social networks through a range of different organisations, religious groups or clubs. Often these groups were unique, and to a certain degree exclusive, to certain communities. Despite the diversity of community groups, and the high levels of engagement, we found that residents typically had relatively few trusted sources of information. Family and close friends often featured prominently, but religious and community leaders were very influential across all communities.

Networks are effective at bringing people together, and disseminating information and messaging to members, and then, through them, the wider community. Such a network of community assets, if properly managed, could be an effective method of communicating with the South Asian population through trusted members and leaders.

Religious organisations were particularly effective at gathering together large numbers of people, and disseminating messaging to them. We found levels of participation in religious worship and associated groups to be relatively high, and as such a great opportunity for meeting the community.

Levels of trust in all organisations and leaders, although particularly religious examples, were high. Religious leaders were accorded a great deal of respect and admiration, and have numerous opportunities to engage with their congregations, therefore rendering them particularly effective communicators. Such community influencers are relatively small in number, and differ from one particular community to the next, but represent a great opportunity for engagement across the board.

Furthermore, we discovered a remarkable enthusiasm to engage amongst all groups, organisations and club we encountered. Group leaders were interested to find out more about our work, and also to gain what they could from us; be it information, resources or guidance. Shaf et al (2014) cite a similar willingness to engage as a result of their research; finding the various organisations engaged with both able and willing to deliver education programmes.

- **Ref: Khunti et al (2011)** Engaging with the community involves going out to them, in the places they shop and talking to people about their lifestyle habits

Many of the community organisations we encountered as part of our fieldwork were already providing some level of support or guidance to members of the community with health problems, including diabetes. This current provision was slightly haphazard, relying on the knowledge and expertise of group leaders, which was limited in some cases, or the attendance of external experts, which was infrequent at best. However, there was always a willingness to better prepare, utilise and support any existing work.

We also felt that some organisations which were not currently engaging in healthcare support or education could be easily encouraged to do so, and would be equally as able as others in terms of delivery.

A more co-ordinated approach from healthcare providers could ensure that messages are delivered within communities, by trusted members, and within already existing structures.

A COHESIVE APPROACH

Knowledge of community or religious organisations and groups was primarily passed on through informal networks and word of mouth. We found very little evidence of an online presence, a co-ordinated strategy or even a membership drive, amongst the vast majority of those engaged with as part of this research. Introductions from family and friends, however, often ensured a relatively high level of commitment, or a willingness to travel further than normal and ‘go out of one’s way’ to attend sessions or meetings.

That said, such an approach means that local healthcare professionals are often completely unaware of the range of services available on their doorstep. Patients, then, who could benefit from existing services within their community may be missing out because of the informal networks used to publicise them.

“I wish I had known earlier about that scheme you have just mentioned. I can already think of so many patients who I could recommend to go!” (Diabetes nurse, TH)

Many of the organisations we encountered were already providing some services that were helpful to diabetes patients, be it some form of exercise, group support or direct advice. What is more, we felt that many organisations could have provided a lot more, with only minimal support and encouragement.

OPPORTUNITIES

- How do we get the community engaged and working to improve self-management themselves?
 - There are numerous opportunities for the messages about better self-management of diabetes, and future prevention of the condition, already existent within the various communities researched throughout this study. Making use of existing community schemes, organisations and trusted message-givers will be crucial to ensuring any work done is well received by patients and the wider community.
 - The enthusiasm for delivering healthcare messages is consistent throughout the various communities studied, and there is a real need for healthcare providers to make the best use of this opportunity to communicate with patients, and future patients, on their terms and in their environment.
 - Messages will be best believed and implemented when they are delivered by those voices within the community that are trusted, and making the most of this will be crucial to successfully tackling diabetes within South Asian communities.

Next Steps

Diabetes will continue to be a problematic condition for the South Asian communities of Thornton Heath into the future if crucial barriers and misconceptions are not addressed by healthcare providers, both NHS and Bromley Healthcare CIC. Both prevention and more effective self-management must be prioritised, in order to minimise the impact of the condition for those currently diagnosed, and make the most of scarce healthcare resources, but also to ensure that the condition does not become more widespread in the future.

That said, there is a great deal of opportunity across all elements of the diabetes experience. The vast majority of this opportunity is to be found in engagement with the variety of community structures and organisations already working within the South Asian communities of Thornton Heath. This network is diverse in terms of the size and reach of each organisation or programme, in terms of the community targeted and the capacity for inciting change. However, all organisations encountered as part of this research were united in their appetite for support and engagement around health issues, including diabetes.

Utilising existing networks

Community and religious groups and organisations have a reach and level of trust that healthcare providers will struggle to replicate. By utilising their enthusiasm for support and combining their trusted voice with clear and accurate information, messages about diabetes, both prevention and self-management, can be delivered into the heart of previously difficult to reach communities. Messaging around medication, herbal remedies and food could be delivered through a variety of channels, giving patients and their peers the chance to ask questions of both professionals and trusted community representatives, and friends.

In order to bust the ‘myths’ surrounding diabetes medication, and the barriers around food and cultural obligations, communities must feel comfortable asking their questions, and understanding the answers given. However, in order to ensure accurate information and messaging is being delivered, programmes around diabetes education must be closely managed and supported by healthcare providers and professionals.

Understanding current provision

Ensuring that healthcare providers and professionals understand the current availability and aim of existing programmes within various communities is a further opportunity to ensure that diabetes patients can access services which meet their specific needs. We encountered a variety of organisations providing services that were helpful for patients with diabetes, and yet these schemes were operating under the radar of healthcare providers. Taking stock of existing provision, at a community level, will help healthcare professionals to provide better signposting and support to their patients.

Work must be done to build relationships between healthcare providers and community organisations, perhaps utilising the work done throughout this research as a starting point. Keeping up to date with those in charge of various schemes and groups requires time and commitment, and will be by no means a simple task for a healthcare provider. However, the rewards of establishing and maintaining such links will be access to services which can help with self-management and prevent future generations developing diabetes.

Empowering women

Across all themes discussed throughout this report, the role of women emerges as a consistent factor. Most prominent in the case of attitudes to food and cultural barriers to culinary change, the position of women and their ability to effect change in their families and communities is crucial to a successful strategy on diabetes.

Ensuring women are able to implement change in the diet of their families, and understand why this is necessary, will be key to changing behaviours around food for the next generation, and helping current diabetes patients better manage their own conditions. Furthermore, making sure that women have access to safe spaces for physical exercise, and understand the importance of it, will mean that lifestyle changes required to effectively manage diabetes are not dismissed at the outset.

Once again, community organisations and trusted voices are the best chance of making a change to the current status quo. Providing information, support and encouragement will enable accurate information and empowerment to be delivered by people who matter within individual communities, and who are most capable of inspiring change, both at an individual and a community level.

Appendix 1

- Maslaha Diabetes (Tower Hamlets – London)
- ‘Diabetes and Me’ South Asian Project in Glasgow
- Apnee Sehat in Leamington Spa
- Khush Dil in Gloucester
- Diosk project in the United States (South Texas)
- ‘Ride the Subway to a Healthy Hearth’ - Swindon Tamil Association
- X-Pert Structured Education Programme (South Asian)
- DESMOND BME

Appendix 2

Interviewees:

- Sobana Anandarajah (Practice Manager, Mersham Medical Centre)
- Louise Andrews (Dietician)
- Michelle Barratt (Head of Service, Bromley Healthcare)
- Dipty Gandhi (Clinical Lead for diabetes for NHS Croydon CCG)
- Sophie Harris (Innovation Fellow – Diabetes at the Health Innovation Network)
- Jessica Hart (Senior Pathways Redesign Manager at Croydon CC)
- Nadia Mensah (Senior Diabetes Specialist Nurse Oxleas NHS Foundation Trust)
- Raheel Mohammed (Director of Maslaha)
- Rajan Namasivayan (Ex Senior Partner at Parchmore Medical Practice. Previously Clinical champion in Primary Care for Croydon PCT President of DUK Croydon branch)
- Nana Oppong (Senior Partner, Mersham Medical Centre)
- Nina Otomoso (Nutritional Therapist)
- Tim Read (Diabetes UK Croydon Group)
- Tanveer Sajjid (General Secretary, Croydon Mosque)
- Prajapa Seneviratne (Project Development Manager at Diabetes UK Scotland)
- Ronesh Sinha (Author of the ‘South Asian Health Solution’)
- Darren Sharpe (Research Fellow at the University of East London)
- Jacqui Stoner (Weightwatchers Thornton Heath)
- Ram Thiagarajah (President of the Swindon Tamil Association)
- Jo Yanzu (Lead Practice Nurse, Parchmore Medical Centre)

Appendix 3

- Shree Sakthy Ganapathy Temple
- Bangladeshi Welfare Association
- Ayurvedic Herbal Care Ltd
- Vishwa Hindu Parishad, Swami Vivekananda Centre
- Raj Yoga Meditation by Brahma Kumaris
- Jagruti Women’s Group
- Asian Resource Centre
- Age UK Croydon
- Thornton Heath Library
- Broad Green Library
- Thornton Heath Leisure Centre
- Norbury Islamic Society
- Ummah Sports
- Keep fit Bollywood Dance for Women
- Ayurmedics Clinic
- Croydon Mosque
- Brigstock Medical Practice
- London Road Medical Practice

- Grainmill Shop
- Khan Halal
- Crystal Palace FC
- Oshwal Mahajanwadi
- Sri Sathya Sai
- Dosa n Chutney
- Croydon Gurdwara
- North Croydon Medical Centre
- Cavendish House Medical Centre
- Mayday Community Pharmacy
- Shivas Pharmacy
- Croydon BME forum
- Mum's the Chef
- Sakhee Sangham
- Surrey Satsung Mandal
- Diabetes UK – Croydon Group
- Croydon Healthy Living Hub

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Thank you