

Diabetes in BME Communities: Raising awareness, improving outcomes and sharing best practice

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Foreword

by Virendra Sharma MP



I am delighted to introduce *Diabetes in BME Communities: raising awareness, improving outcomes and sharing best practice*, a report which outlines the barriers to improving outcomes for people with type 2 diabetes in black and minority ethnic (BME) communities and identifies examples of best practice to support South Asian, black African and black African Caribbean people to better manage their diabetes.

In 2008/9 I chaired the Diabetes in the South Asian Community: Parliamentary Best Practice Consensus Group to look into the specific reasons why South Asian communities are at a much higher risk of developing type 2 diabetes and which interventions were making a difference.

This report is a timely and important update as a lot has changed since then. GPs have greater control over the services their patients are using, local authorities have new public health responsibilities and the NHS is facing significant financial challenges. This drastic change to the environment means that healthcare professionals, commissioners and patients must do more to manage chronic conditions in more efficient and cost effective ways.

In order to tackle the significant challenge that type 2 diabetes presents BME communities, I decided to convene a working group in Parliament. The members of the working group were chosen for their valuable insight into diabetes in BME communities. Their knowledge, research and contributions have been invaluable in identifying the problems facing BME communities and the examples of best practice which exist in the NHS.

The group has recommended that investment in prevention, early diagnosis and active treatment, in tandem with promoting the value of culturally relevant interventions, is integral if we are going to provide better care and improve outcomes for diabetes patients in BME groups.

My constituency of Ealing Southall is one of the most ethnically diverse in the country, and it is estimated that Ealing CCG has over 23,000 people with diagnosed and undiagnosed diabetes. I am keen to do all that I can to help raise awareness of the higher risk of type 2 diabetes in ethnic minorities and also, of the disastrous consequences that type 2 diabetes can have if left undiagnosed and untreated. I am grateful to the members of the group for their contributions, and for the support of Janssen as we work together to improve outcomes across all communities.

A handwritten signature in black ink that reads "V Sharma". The signature is stylized with a large, looped 'V' and a cursive 'Sharma'.

Virendra Sharma MP
Chair, Diabetes in BME Communities Working Group

Executive Summary:

Diabetes in BME Communities

Over 3.2 million people have been diagnosed with diabetes in the UK and a further estimated 500,000 people have the disease but are unaware.^{1,2} By 2020 it is expected that more than 3.8 million people will have developed diabetes in the UK, rising to more than 5 million by 2025.^{2,3} Current estimates suggest that type 2 diabetes costs the NHS £8.8 billion, with 80 per cent of this spent on treating avoidable complications such as cardiovascular disorders.² Nearly 250,000 people were diagnosed with diabetes last year.²

Diabetes is a major cause of complications such as amputation, working age blindness, stroke and renal failure.² There are an estimated 20,000 avoidable deaths due to the poor management of diabetes every year.² This can place a large strain on hospitals. One in six hospital beds in England are occupied by someone with diabetes, and diabetes accounts for over 600,000 excess bed days every year.⁴

It is well known that people from South Asian, black African and black African Caribbean populations carry a considerably larger risk of developing type 2 diabetes.⁵ Compared with the white general population South Asians are up to six times more likely to develop type 2 diabetes.⁵ Furthermore, people from African or African Caribbean descent are up to five times more likely to develop type 2 diabetes than the general population.⁶ Figures from the 2011 Census and the Yorkshire and Humber Public Health Observatory suggest that over 500,000 people from BME backgrounds and communities have diabetes in England.^{7,8}

Evidence from the National Diabetes Audit indicates that diagnosed rates of type 2 diabetes in BME Communities increased by 21 per cent between 2009/10 and 2011/12, compared with a 14 per cent increase in the white population over the same period.⁹

Furthermore, people from BME backgrounds are much more likely to face socioeconomic problems and this can have an impact on health outcomes. The most deprived people in the UK are over two and half times more likely to develop diabetes than the rest of the population. Moreover, the complications of diabetes, such as heart disease, stroke and kidney failure, are three and half times higher in lower socioeconomic groups.⁶ In addition, there is evidence showing that deprivation and ethnic background impact a person's likelihood to access healthcare.¹⁰ BME groups face considerable barriers to accessing appropriate services and support and this is clearly having an impact on patient outcomes.

In 2012 the Southall and Brent Revisited (SABRE) study concluded that almost half of all people of South Asian, black African and black African Caribbean decent will develop diabetes by age 80.¹¹ Census data indicates that there are over 5 million people in the BME population, and that the UK population is still growing.^{7,12} This raises considerable concerns about the ability of the NHS

to manage the potential implications of this diabetes epidemic. Diabetes in BME communities is a significant health inequality and improving outcomes across England will depend on improving awareness and understanding in BME communities, and the quality of care that these people receive.



The scope

The working group was convened to discuss and critically assess the impact of diabetes in BME communities; to identify the barriers to improving outcomes and to share their knowledge of best practice initiatives to improve diabetes care in the NHS that could be implemented in other areas. The group covered issues such as the increased prevalence of diabetes in BME communities; differences in rates of complications; how to identify and mitigate the key cultural and ethnic barriers to raising awareness of diabetes; and to highlight the opportunities that the new NHS structures present.

The report

The report is designed to provide commissioners, clinical experts, clinical commissioning groups (CCGs), GPs, specialist nurses, other health professionals, politicians and health policy makers with a clear insight and understanding of how they might be able to improve service provision to BME communities across England.

Participants

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Acknowledgements

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Contact

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Improving outcomes in BME communities – working group recommendations

The increasing prevalence and poor outcomes of people with type 2 diabetes in South Asian, black African and black African Caribbean communities is a significant health inequality. National and local commissioners must act to identify those people at high risk of developing diabetes, provide education to families and communities, and remove the barriers which prevent people from engaging with their condition earlier.

National

1. The disproportionate burden of diabetes complications in BME communities will only be addressed when patients are active participants in decisions made about their own care. In line with the Action for Diabetes strategy, **NHS England** should support commissioners and clinicians to implement the 'House of Care' model and should prioritise 'Year of care' payments for patients with diabetes.
2. **Public Health England** should work with **patient and community groups** to develop a community awareness initiative such as a 'national diabetes in BME communities awareness week'. Furthermore, this should be supported by role models from different BME communities to raise awareness of dangers of diabetes and obesity.
3. Given that the development of diabetes varies according to ethnicity, and that BME groups are less likely to meet treatment thresholds, the **National Institute of Health and Care Excellence** should consider whether in its Guidance and Guidelines, the thresholds for intervention for HbA1C, blood pressure and cholesterol should be tailored to each ethnic group.
4. **Public Health England** should work with **national patient groups and local community groups** to ensure that different BME communities can access appropriate and culturally sensitive dietary information, and that this information is disseminated in innovative ways. Dietary information and lifestyle support has to resonate and be applicable with people's lives.
5. There is a pressing need to build on existing research exploring the reasons why different ethnic groups experience varying rates of diabetes complications and outcomes. Furthermore, it is essential that this information is used to tailor NHS policy to the specific needs of these communities.

"In the African-Caribbean community when I was growing up, there was almost an assumption that as you got older you would have higher blood sugar levels.

People talked about it as though it was just part of life. We have to explain to people that it is not inevitable at all if you watch your diet, and also to give them diet advice that sits with what they want to eat."

DIANE ABBOTT MP

Local

1. **CCGs** should work with **health and wellbeing boards** to develop strategies to improve the identification of people at risk of diabetes in BME communities, to raise awareness of the specific risks that these communities face, and to tailor appropriate and culturally sensitive advice and education specifically for BME communities. **Health and wellbeing boards** should ensure that JSNAs review health data on BME groups including South Asian, black African and black African Caribbean people with, or at risk, of diabetes.
2. Each **health and wellbeing board** should appoint a BME lead to ensure strategy and interventions to tackle health inequalities are delivered.
3. **Public Health England and local authorities** should commit to targeting the NHS Health Check at people from the age of 25 onwards in BME communities.
4. **Local commissioners and healthcare professionals** must seek to raise awareness beyond traditional healthcare environments. Information about diabetes should be accessible and available in public spaces where people live, work, travel and shop.
5. In partnership with **local authorities** and **commissioners**, it is essential that **clinicians** recognise the value of extending healthcare beyond individuals to families and communities. Individuals who have prominent positions in the social structures of different communities are vital as a means to raising awareness of diabetes and obesity, and reaching families and individuals who do not access healthcare services in traditional ways. **Local authorities** should offer training to local religious, cultural, social and business leaders in diabetes awareness and understanding so that they can educate people as part of their everyday work.
6. **Directors of Public Health, health and wellbeing boards, CCGs and healthcare professionals** need to work together to embed awareness and education of diabetes in primary and secondary education; develop appropriate and culturally sensitive leisure facilities; and ensure that the planning of public spaces recognises the distinct healthcare challenges facing our changing population.
7. Childhood obesity is a driving force of high rates of adult diabetes in the UK, and this is a particular concern for children from BME backgrounds. **Local authorities** have to manage this trajectory through improving access to healthcare in schools, and through improving the ability of children to understand the difference between healthy and unhealthy food from an early age. Furthermore, parents should also receive education and support to help manage their child's health.
8. **Healthcare professionals** should receive training to recognise the cultural, clinical and social differences that exist within and between South Asian, black African and black African Caribbean communities.
9. Local commissioners should engage with BME communities and local providers to ensure that services are in place to meet local needs. This can be through traditional and social media, community events, employment venues and places of worship.
10. Empowering patients by ensuring that they can access their own healthcare records is only useful if patients can fully understand the information that they have. **Health and social care professionals** must explain technical information to patients. This will help to build trust between healthcare professionals and different ethnic groups and communities.

Diabetes in the NHS – a policy overview

The NHS is facing an unprecedented challenge of trying to meet dramatically increasing demand for healthcare, driven by a growing and ageing population, whilst trying to achieve efficiency savings to manage a projected gap in funding. This was initially articulated as the Nicholson Challenge, to achieve four per cent year on year efficiency savings until 2014. However, NHS England has extended these projections in *The NHS belongs to the people: A call to action* which identifies an additional £30bn of savings required by 2020/21.¹³

As a way of meeting this challenge, the Government introduced the Health and Social Care Act 2012 which has dramatically changed the healthcare landscape. The Act introduced new structures and organisations to lead on the commissioning and delivery of care. These new structures are underpinned by a shift in emphasis towards achieving improved outcomes across disease areas, articulated by the NHS Outcomes Framework and the Mandate, and over-arching strategies such as the Cardiovascular Disease Outcomes Strategy.^{14,15,16} This is necessary to meet the needs of the projected 2.9 million people set to develop multiple long term conditions.¹⁷ Furthermore, the Government's focus on localism provides an opportunity for local authorities, health and wellbeing boards and CCGs to shape services to meet the particular needs of the populations that they serve.

In December 2013 NHS England published *Everyone Counts: National Planning Guidance 2014-2019* which seeks to build a long term approach to financial management and the planning of patient care in the NHS. The guidance is designed to encourage coordinated planning at a national and local level to help the NHS meet the demographic and financial challenges it faces in the near future.¹⁸ This includes the substantial costs generated by the increased prevalence of diabetes in BME communities combined with poorer outcomes in this group. Tackling these significant health inequalities in diabetes in BME communities will depend on empowering patients, improving education and awareness of diabetes, providing integrated care across primary, secondary and social care and ensuring that patients can access the highest quality emergency care, especially for those patients with multi-morbidities.



National Strategies to tackle diabetes

In January 2014, NHS England introduced *Action for Diabetes*, which sets out a vision for diabetes services in the NHS. This was released in response to the Public Accounts Committee report on adult diabetes services published in 2012.¹⁹ *Action for Diabetes* outlines a number of priorities that span across the five domains of the NHS Outcomes Framework. These include: making personalised and integrated diabetes care a reality; reducing diabetes emergency admissions and empowering patients to manage their own diabetes safely; ensuring everyone with a long term condition has a holistic, personalised care plan, and improving health literacy. The commitment to provide health literacy training to 10,000 people in disadvantaged communities will have an important impact on health inequalities in BME communities, and is welcomed by the working group.

Additionally, the report outlines NHS England's support for the 'house of care' model of integrated care for diabetes patients. This model describes a whole system approach to managing diabetes where informed patients, engaged healthcare professionals, informed commissioning and organisational processes are brought together to deliver personalised care plans that recognise the unique needs of each patient.¹⁷ *Action for Diabetes* will need to be addressed within the broader strategies of the Cardiovascular Disease Outcomes Strategy (CVD), the NHS Outcomes Framework, the Mandate and the Public Health Outcomes Framework.

Variation in access to services and patient outcomes

It is essential that CCGs, health and wellbeing boards and local authorities are fully aware of the needs of their local populations, and are implementing best practice as outlined by the National Institute of Health and Care Excellence (NICE) quality standards and clinical guidelines.

Outcomes for patients with diabetes have improved, as evidenced by the Global Burden of Disease Study published in the Lancet in 2013, which highlights that the UK has the lowest premature mortality attributable to diabetes of the 19 wealthy countries included in the analysis.²⁰ However there was criticism from the Public Accounts Committee and the National Audit Office prior to this publication, suggesting that services for people with diabetes could be improved.^{3, 21} Furthermore, evidence indicates that people living in the best performing CCGs are four times more likely to receive the eight key checks* recommended by NICE than those people living in the worst performing CCGs.²

However, it is important to recognise that CCGs are facing significant challenges and it is essential to ensure that best practice in identifying and educating people at risk of diabetes is implemented more widely across the country to drive long term improvements in outcomes. In order to facilitate the uptake of best practice in BME communities, commissioners should, where appropriate, be encouraged to identify examples of service provision in other areas which have helped to shape the design of their service.

*NICE recommends measurement of the following nine key care processes: HbA1c, blood pressure, cholesterol, serum creatinine, urine albumin, foot surveillance, BMI, smoking status, eye screening (eye screen not recorded on the 2011/12 National Diabetes Audit).

Working group discussion

The working group, convened in November 2013, brought together a range of views and ideas on how to improve outcomes in BME communities. At the heart of the discussion was the recognition that BME communities, particularly South Asian, black African and black African Caribbean communities, have a significantly increased chance of developing type 2 diabetes. Furthermore, it was recognised that the burden of disease in these communities is considerable. This is not sustainable for the NHS with the financial and demographic challenges it faces in the short and long term future.

The discussion focused on three central challenges facing clinicians, commissioners, local authorities and people in BME communities:

- the barriers to accessing healthcare and support for people with, or at risk, of diabetes in BME communities;
- how to improve our collective understanding of diabetes and why different people experience a range of complications;
- to ensure that the NHS works for patients by introducing funding flows and financial incentives that support efforts to improve outcomes for people with chronic conditions like diabetes.

i) Prevalence and complications of diabetes

It is well known that people from a South Asian family background are six times more likely to develop diabetes than people of white European origin.⁵ In black African and black African Caribbean communities, diabetes is up to five times more prevalent than in people of white European origin.⁶

Statistics indicate that up to 20 per cent of the South Asian community and 17 per cent of people from black ethnic groups living in the UK have type 2 diabetes in contrast with 3 per cent of the general population.⁶ In total, over 500,000 people from BME communities may have diabetes, including one in two people aged over 80 in BME communities, compared with only one in five people over the age of 80 in the white European population.^{7, 8, 11}

The working group emphasised the necessity for clinicians and commissioners to appreciate the differences within and between the different ethnic groups. This is essential for fully understanding the clinical consequences of a person from these ethnic backgrounds developing type 2 diabetes. For example, it was noted that people with diabetes from a South Asian background have a much higher chance of developing heart disease and end-stage renal failure than white Europeans who develop diabetes. However people from black African Caribbean backgrounds are more likely to develop hypertension and have harder to control blood pressure, which contributes to greater incidences of stroke.

In addition, the working group indicated that people from black African Caribbean backgrounds are relatively protected from coronary heart disease, compared with white Europeans and with people from South Asian backgrounds who are at a much greater risk. Furthermore, evidence suggests that people from South Asian and black African Caribbean backgrounds have a much lower incidence of diabetic foot complications and thus a lower rate of amputations than the white European population. However, due to the greater number of people per head with diabetes, the disease burden is still greater in these ethnic groups than the white European population.²²

"Driving the higher prevalence of type 2 diabetes that we are seeing year on year is obesity"

PROFESSOR JONATHAN VALABHJI, NATIONAL CLINICAL DIRECTOR FOR OBESITY AND DIABETES



Understanding these complex differences is essential for improving our understanding of diabetes and tailoring services to effectively manage patient outcomes. The development of diabetes is diverse. While there are clear genetic, social and cultural components, there is real lack of evidence to explain why there are varying complication rates in different ethnic groups. There is a real need for further research to explore the differences in rates of complications in different ethnic groups. Academic Health Science Networks should work with Strategic Clinical Networks to build on existing research in this area.

Furthermore, polypharmacy is a particular issue and one that is set to increase. The number of people with multiple chronic conditions is expected to increase from 1.9 million in 2008 to 2.9 million in 2018.¹⁷ The Glasgow Minority Ethnic Long Term Medicines Service (MELTs) is an excellent example of a service which reaches out into BME communities to provide useful advice about different medications and with the support of the pharmacists make changes to medication regimes.²³ This is important as up to two thirds of type 2 diabetics do not take their oral hypoglycemic medication as prescribed.²⁴ Pharmacists have an integral role to play in the management of medication regimes for patients with long term conditions who are likely to be taking multiple medications.

"Diabetes is a much more heterogeneous disease than the conventional subdivision into type 1 and type 2 diabetes assumes. Type 2 diabetes, particularly, has many faces and is highly heterogeneous"

THE LANCET²⁵

The central processes underlying the development of diabetes are diverse, and as noted by the Lancet, our understanding of diabetes as a single disease is misplaced. Research conducted in the US highlighted ethnic variation in the way that diabetes develops. East Asian populations are more likely to have diminished insulin-secretion ability but have normal insulin resistance, while people of African origin are more likely to have higher insulin resistance but have higher insulin secretion. Caucasians fell between these two groups, though they were more likely to develop problems with insulin secretion.²⁶

Studies have highlighted that diabetes in South Asians develops five to ten years earlier than in white Europeans.²⁷ Evidence indicates that South Asians are more insulin resistant than white Europeans and that this might be due to increased adiposity, abdominal fat and the impact of metabolically active intra-abdominal fat.²⁷



The consequence of these differences is that people from different ethnic groups are developing diabetes in different ways and that it is necessary to review how clinicians manage risk factors that lead to interventions. For example, studies have indicated that South Asians, black Africans and black African Caribbeans are significantly less likely to meet national treatment targets for HbA1c, blood pressure and cholesterol.²⁷

This suggests that the threshold for intervention should be reviewed and potentially tailored according to the risk factors associated with each ethnic group. Healthcare professionals should receive additional training to improve their awareness and understanding of the development of diabetes in different ethnic groups.

NICE public health guidance on preventing diabetes in high risk individuals (PH38) suggests that local commissioning plans invite South Asian and Chinese people aged 25 and over for a risk assessment every five years.²⁸ The working group suggested that the NHS health check should be extended to people aged over 25 in at-risk groups compared with those aged over 40 in the general population. However, now that the commissioning of the NHS health check programme is the responsibility of local authorities there is a concern that patient access to these services may vary across the country. In 2011/12 only 19 per cent of eligible people in London were offered a NHS health check, and in some boroughs the check was offered to as little as 2 per cent of people.²⁹ It is well known that local authorities across England have to make very difficult financial decisions in the current economic environment, and this may impact on the delivery of the NHS health check programme.

ii) Obesity and childhood obesity

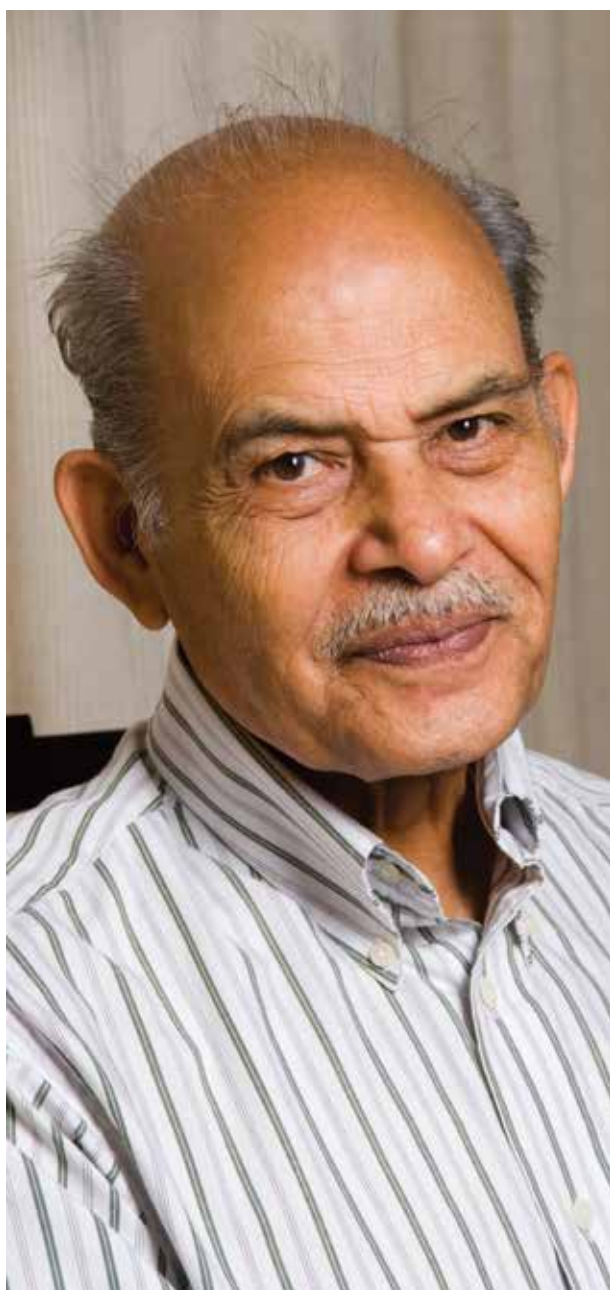
The obesity epidemic has caused a parallel rise in type 2 diabetes across much of the developed world. Tackling obesity at national and local levels must be a priority. Over 23 per cent of adults in the UK are clinically obese and 61 per cent are considered to be overweight or obese.³⁰ With over seven million people at-risk of developing diabetes in the UK, there is a considerable need to ensure that existing interventions are working and to develop services to improve outcomes further.²

The working group noted that rates of obesity in children are rising and that this can be considered to be one of the largest public health challenges facing England. Evidence indicates that 17-20 per cent of 11 year old children are not just overweight (which is a BMI of 25-30) but are considered to be obese (a BMI of 30+). Furthermore, 23.1 per cent of four to five year-olds are overweight or obese, and 33.3 per cent of 10-11 year-olds are overweight or obese.^{30, 31} Further to this, children from BME communities are more likely to be obese or overweight than children from a white European background.³¹ The working group was keen to stress the importance of ensuring that children are well educated about the dangers of obesity and the risks of developing type 2 diabetes. It was suggested that teaching children how to cook and understand the difference between healthy and unhealthy food would be beneficial.

In the course of the discussion, members of the working group discussed the excellent health outcomes that children in Finland experience. In Finland, when a child starts to attend school they are immediately enrolled into the school healthcare system. Children receive annual check-ups with the school nurse, in depth examinations in their first, fifth and eighth year, and personalised advice to support mental health, independence and physical fitness.³²

While reproducing this model in England would be difficult, there was consensus that improving regular access to healthcare for children could have beneficial outcomes over the long term. Partnership working between local authorities, schools, clinicians and commissioners will be essential in reversing the rise in childhood obesity and the consequently inevitable increases in the number of people with type 2 diabetes.

Furthermore, empowering young people to take control of their health can have beneficial outcomes. Portsmouth NHS Trust has developed an adolescent and young people transition service, designed in partnership with young people, which aims to increase their understanding of diabetes and their control over their symptoms. The programme managed to reduce 'did not show' rates to 10-15 per cent (from 40-50 per cent) and diabetes ketoacidosis admissions by 11 per cent (See annex for case study). While this service is aimed at patients with type 1 diabetes there are valuable lessons that can be applied to services for adolescents and young people with type 2 diabetes.



iii) Diet

Lifestyle factors such as diet, rates of physical exercise and the prevalence of smoking all contribute to the development of type 2 diabetes. Members of the working group identified dietary advice as a particular cause for concern. While information on eating healthier food and adapting meals to lower the levels of salt, sugar and fat is available, for many ethnic minorities it may not be appropriate. For example, a person with Jamaican heritage will have very different culinary traditions compared to a person from St. Lucia.

The same problem is inherent in South Asian communities. It was suggested that more work needs to be done to ensure that people from different ethnic backgrounds are able to access dietary advice that is culturally sensitive and meaningful to their everyday lives. Furthermore, this should be developed by people who fully understand the different culinary cultures and traditions that exist in England.

There is a real need for healthcare professionals and community leaders to provide advice to support people to meet their religious and cultural commitments. Many Muslims are passionate about fasting during the month of Ramadan, and while the Quran exempts people who are sick from undertaking this duty, a recent study found that 79 per cent of people with type 2 diabetes (across 13 Muslim countries) fast during Ramadan.³³ This is problematic as it can increase the risk of hypoglycemic and hyperglycemic events.

As part of their Community Champions project, Diabetes UK launched a Ramadan pilot project in London. Volunteers from African and African British backgrounds created online presentations and videos which showed people talking about their decision to fast during Ramadan. The volunteers visited mosques and encouraged people with diabetes to talk to their imam or a healthcare professional before making the decision to fast.³⁴ Furthermore, the Silver Star Appeal launched the 'Staying Healthy During Ramadan' initiative which encouraged local GPs to visit mosques to raise awareness of the dangers of unprepared fasting for people type 2 diabetes, and also to provide education on how to fast safely. Furthermore, nurses also attended the mosques to provide blood glucose tests using the Silver Star mobile diabetes units.³⁵ It is essential that Muslim patients are supported to make the best decision for their long term health during Ramadan through the provision of information and consultations with their GP or multidisciplinary team.

"We are developing a resource at the moment around healthy eating with specifically African foods and diets, because one of the biggest problems people have is that they are given healthy eating advice that does not make any sense to them. Our work was triggered by one of our members who was advised that she was at risk of diabetes and given a recipe book. She did not understand what any of the recipes were. She had never made them, she was never likely to make them, and she had no idea how to make her food healthy"

JACQUELINE STEVENSON, ACTING CHIEF EXECUTIVE, AFRICAN HEALTH POLICY NETWORK

Providing access to a dietician can encourage people to improve their diets. The Prevention of Diabetes and Obesity in South Asians (PODOSA) study suggests that a culturally adapted, family-based lifestyle intervention service can provide improved outcomes over the standard provision of information and follow-up in a clinic based environment. In the study individuals from a South Asian background would be visited by a dietician roughly 15 times over three years in their own home. The family cook had to be enrolled in the programme to ensure that the whole family could benefit from the intervention. The programme resulted in greater weight loss, reductions in BMI and reductions in waist circumference when compared with the control group.³⁶

Several working group members discussed the lack of appropriate dietary advice and support in African and African Caribbean communities. The diversity in the types of food consumed and in the way that food is prepared means that developing this resource is a considerable challenge. The working group believes that future work should be done to develop appropriate dietary advice, and that Public Health England should ensure that this is disseminated effectively.



iv) Physical Exercise

Research has shown that levels of exercise vary within and between different ethnic groups.³⁷

On average, British ethnic minorities do considerably less physical activity than the white British population. However members of the working group suggested that while this applies to the younger generation of ethnic minorities the problem is not as pronounced as in older generations. Given the increased risk of developing type 2 diabetes the working group has recommended that ethnic minorities should exercise for more than the half an hour per day recommended for the white population.

Improving levels of physical activity is difficult. Interventions such as discounted and free gym membership can be important but the barriers to accessing these facilities are not always financial. Local authorities should ensure that leisure facilities provide services which are appropriate, respect cultural and religious norms, and allow people to feel comfortable. However, it was noted that while improving access to gym membership is important, many people do not maintain this lifestyle change or increase their calorie intake to match their increased activity. Instead, encouraging smaller, everyday changes such as walking to the shop rather than using the car, or using the stairs rather than a lift can have a much more beneficial impact over 20 years and, crucially, can be much easier to sustain.

People from all communities and ethnic backgrounds must be able to access services to improve their health. At a local level, it is imperative that local authorities recognise the structural barriers that prevent people from different ethnicities, religions, age groups and genders from accessing appropriate health and community services. Educating and empowering people is only useful if they are able to access the support and services required to make vital lifestyle changes.



v) Raising awareness and understanding of diabetes in BME Communities

Ensuring that people in BME communities understand their increased risk of developing diabetes and the links between type 2 diabetes and obesity is essential. Outreach programmes like the Silver Star Appeal mobile diabetes unit, the annual Preston health mela and the Apnee Sehat specialist intervention clinics reach out to BME communities to raise awareness and offer advice and health checks.^{38,39,40} There is a clear recognition amongst community and third sector groups that healthcare interventions targeting BME communities must be delivered beyond traditional healthcare environments.

The Diabetes UK Community Champions project offers diabetes awareness training, advice and support to local religious, cultural and social leaders.⁴¹ These people are embedded in community structures and command the trust and respect of local people. Many of these interventions are primarily focussed in South Asian communities and, despite the work being conducted by organisations like Diabetes UK, there is an urgent need for more services to be developed in black African and black African Caribbean communities in England. Public Health England and local authorities should work in partnership with community groups to ensure that this becomes a reality.

Building trust between the NHS and BME communities should also be a priority for improving outcomes. The working group noted that some communities do not trust healthcare professionals and are concerned that they might not receive the best advice and care. The BME Leadership Forum suggests that organisations should develop a diverse workforce that understands the community that they serve. This should be supported by a very clear equality vision with specific action plans to tackle inequalities, like diabetes, and by recruiting people from BME communities to be non-executive board members.⁴²

"In many cultures African women especially seek to be a larger weight, so health interventions that tell them they lose weight because they will look better or feel better do not have any meaning. It does not resonate with their own lives. We need to engage with communities to lead change themselves, and support existing community structures to respond"

JACQUELINE STEVENSON, ACTING CHIEF EXECUTIVE,
AFRICAN HEALTH POLICY NETWORK

"The encouragement that comes from children is very important, and I think it is now working. I did not see this ten years ago: I can see the change"

VIRENDRA SHARMA MP, CHAIR OF THE DIABETES IN BME COMMUNITIES WORKING GROUP

The working group believes that the focus must now be on empowering patients to take control of their life and manage their illness effectively. Many of the case studies in this report are successful because patients who engage with these services are empowered to make better decisions affecting their everyday lives. This is supported by Grace et al, who conducted a large scale qualitative survey of 147 people in east London, and identified that a lack of basic knowledge was not a particular problem for the people they surveyed.⁴³ Rather, they suggested that healthcare professionals should receive training to improve their understanding about different cultures, and that there was a need to move beyond the provision of simple information.⁴³ Ensuring that patients are given access to education so that they can understand how to control their illness is recognised as an essential component of diabetes care. This is especially important for patients with type 2 diabetes which, in some cases, can be managed effectively through exercise, diet and lifestyle changes. However, despite access to education being a NICE recommendation, Diabetes UK found that 31 per cent of people report that they had never been offered structured education, even at their initial diagnosis.²

How patient education is delivered can also be significant. The working group noted that educating the whole family rather than just the person diagnosed with diabetes can have a positive impact. It was suggested that the role of the family is more enhanced in BME communities than in contemporary white British culture, and that this represents an opportunity for healthcare practitioners to influence the family unit on how to control their diabetes symptoms and manage the risk factors for developing diabetes. Furthermore, providing education in schools about the risks of obesity and diabetes can filter through to older generations as children relay the information at home.

The working group highlighted that interventions like motivational interviewing could potentially have an impact on how healthcare professionals communicate diabetes advice – resulting in improving understanding and behavioural change. Research in Denmark found that training GPs in motivational interviewing (MI) can encourage type 2 diabetes patients to become more autonomous, more motivated to change their behaviour and more conscious of the importance of controlling their diabetes.⁴⁴ In this study, GPs who received training in MI were much more likely to pass on key information about exercise, dietary improvement and smoking and alcohol control than those GPs in the control group. In this context, the provision of information, and how it is communicated, had an important impact on type 2 diabetes patients.

"We discovered that a way to influence families is to do it through the children; children come back and start telling their elders, and they set an example. So you influence the family"

DR ETHELDREDA KONG, CHAIR AND CO-CLINICAL DIRECTOR, BRENT CLINICAL COMMISSIONING GROUP

Allowing patients to access their own health records has been used across the NHS to improve the management of chronic conditions. The working group stressed the importance of ensuring that patients can access their health information from GPs and hospitals, and crucially, that they are able to understand the results of different tests. While some GPs in England are leading the way in ensuring that patients are empowered, anecdotal evidence suggests that many GPs still believe that patients shouldn't have access to their own information.

Empowering patients to understand diabetes and to demand key tests is essential for driving improved outcomes. Patient-held records are a popular way of ensuring that both patients and clinicians have access to a range of information about a patient's diabetes progression. However it is essential that all healthcare professionals are committed to implementing patient held records for them to be effective. The University Hospitals of Leicester NHS Trust produced a personal diabetes handbook which provides patients with information about the impact that diabetes can have and what to do in emergencies as well as allowing patients to record information about their diabetes, record their test results and identify their personal targets.⁴⁵

"The benefits of patient-held records are numerous. At the very least, the patient can check their own records to see what mistakes are on them. We have some very good GP champions across the country who are pushing patient-held records and empowering patients to be at the heart of their own care; I think that is the way forward."

DR HABIB NAQVI, SENIOR EQUALITY MANAGER,
NHS ENGLAND

vi) Partnership and integrated care

NHS England's strategy Action for Diabetes identifies integrated care as an essential development in improving outcomes across diabetes care. Specifically, the strategy highlights the importance of introducing 'year of care' tariffs and the 'house of care' model of integration.¹⁹

The working group acknowledged that implementing 'year of care' tariffs could make funding flows support patients to access the care they need at the right time and in the right place. The current payment by results model does not support patients with chronic and multiple long term conditions. The complications of diabetes cost the NHS nearly £8 billion every year and over 20,000 die every year due to avoidable complications.² The high burden of disease and high levels of social economic deprivation in BME communities also suggests that black African, African Caribbean and South Asian people are disproportionately affected by complications.

"I think that the year of care models are fantastic, where you put the patient at the centre and say 'This is what you should expect in a year of your diabetes' and they can go to their healthcare practitioner and say 'you have not done this yet, I need this ticked off.'"

PHILIP NEWLAND-JONES, ADVANCED SPECIALIST
PHARMACIST FOR DIABETES AND ENDOCRINOLOGY,
UNIVERSITY HOSPITALS SOUTHAMPTON NHS TRUST

The Government's emphasis on localism and the transfer of public health responsibilities to local authorities presents a unique opportunity for local stakeholders to have a considerable impact on healthcare services in their localities. However, success will require organisations to work in partnership. Directors of Public Health, health and wellbeing boards, CCGs and individual clinicians need to work together to embed awareness-raising and education of diabetes in primary and secondary education; develop appropriate and sensitive community facilities; and to ensure that the planning of public spaces recognises the distinct healthcare challenges facing their rapidly changing populations.

Where local authorities and healthcare professionals work together in partnership, local people can expect to benefit greatly. In Ealing, the Communities Against Diabetes project brings the local authority, Ealing CCG, the voluntary sector and clinicians together to raise awareness of diabetes in the borough. The partnership has allowed the project to reach health centres, places of worship, housing projects, social care and children's centres.⁴⁶ This approach to establishing partnerships across multiple organisations with different responsibilities should be adopted across the NHS and local government to reach out to the 500,000 people who have diabetes but are currently unaware.²

Improving outcomes in BME communities – working group recommendations

The increasing prevalence and poor outcomes of people with type 2 diabetes in South Asian, black African and black African Caribbean communities is a significant health inequality. National and local commissioners must act to identify those people at high risk of developing diabetes, provide education to families and communities, and remove the barriers which prevent people from engaging with their condition earlier.

National

1. The disproportionate burden of diabetes complications in BME communities will only be addressed when patients are active participants in decisions made about their own care. In line with the Action for Diabetes strategy, **NHS England** should support commissioners and clinicians to implement the 'House of Care' model and should prioritise 'Year of care' payments for patients with diabetes.
2. **Public Health England** should work with patient and community groups to develop a community awareness initiative such as a 'national diabetes in BME communities awareness week'. Furthermore, this should be supported by role models from different BME communities to raise awareness of dangers of diabetes and obesity.
3. Given that the development of diabetes varies according to ethnicity, and that BME groups are less likely to meet treatment thresholds, the **National Institute of Health and Care Excellence** should consider whether in its Guidance and Guidelines, the thresholds for intervention for HbA1C, blood pressure and cholesterol should be tailored to each ethnic group.
4. **Public Health England** should work with **national patient groups** and **local community groups** to ensure that different BME communities can access appropriate and culturally sensitive dietary information, and that this information is disseminated in innovative ways. Dietary information and lifestyle support has to resonate and be applicable with people's lives.
5. There is a pressing need to build on existing research exploring the reasons why different ethnic groups experience varying rates of diabetes complications and outcomes. Furthermore, it is essential that this information is used to tailor NHS policy to the specific needs of these communities.

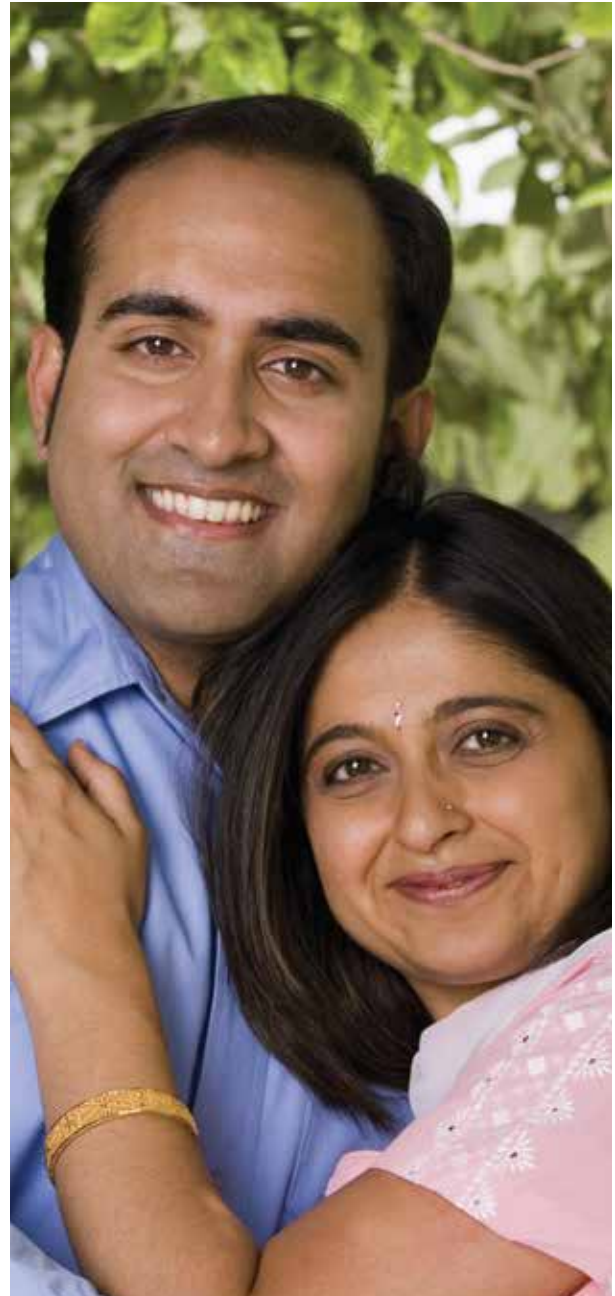
Local

1. CCGs should work with **health and wellbeing boards** to develop strategies to improve identification of people at risk of diabetes in BME communities, to raise awareness of the specific risks that these communities face, and to tailor appropriate and culturally sensitive advice and education specifically for BME communities. **Health and wellbeing boards** should ensure that JSNAs review health data on BME groups including South Asian and black African Caribbean people with, or at risk, of diabetes.
2. Each **health and wellbeing board** should appoint a BME lead to ensure strategy and interventions to tackle health inequalities are delivered.
3. **Public Health England** and **local authorities** should commit to targeting the NHS Health Check at people from the age of 25 onwards in BME communities.
4. **Local commissioners** and **healthcare professionals** must seek to raise awareness beyond traditional healthcare environments. Information about diabetes should be accessible and available in public spaces where people live, work, travel and shop.
5. In partnership with **local authorities** and **commissioners**, it is essential that **clinicians** recognise the value of extending healthcare beyond individuals to families and communities. Individuals who have prominent positions in the social structures of different communities are vital as a means to raising awareness of diabetes and obesity, and reaching families and individuals who do not access healthcare services in traditional ways. Local authorities should offer training to local religious, cultural, social and business leaders in diabetes awareness and understanding so that they can educate people as part of their everyday work.
6. **Directors of Public Health, health and wellbeing boards, CCGs and healthcare professionals** need to work together to embed awareness and education of diabetes in primary and secondary education; develop appropriate and culturally sensitive leisure facilities; and ensure that the planning of public spaces recognises the distinct healthcare challenges facing our changing population.
7. Childhood obesity is the driving force of high rates of adult diabetes in the UK, and this is a particular concern for children from BME backgrounds. **Local authorities** have to manage this trajectory through improving access to healthcare in schools, and through improving the ability of children to understand the difference between healthy and unhealthy food from an early age. Furthermore, parents should also receive education and support to help manage their child's health.
8. **Healthcare professionals** should receive training to appreciate the cultural, clinical and social differences that exist within and between South Asian, black African and black African Caribbean communities.
9. **Local commissioners** should engage with BME communities and local providers to ensure that services are in place to meet local needs. This can be through traditional and social media, community events, employment venues and places of worship.
10. Empowering patients by ensuring that they can access their own healthcare records is only useful if patients can fully understand the information that they have. **Health and social care professionals** must explain technical information to patients. This will help to build trust between healthcare professionals and **different ethnic groups and communities**.

Interventions to improve outcomes in BME communities

The increasing prevalence and poor outcomes of people with type 2 diabetes in South Asian, black African and black African Caribbean communities is a significant health inequality.

National and local commissioners must act to identify those people at high risk of developing diabetes, provide education to families and communities, and remove the barriers which prevent people from engaging with their condition earlier.



Case Study 1:

Communities Against Diabetes (CAD) project

Overview

Southall Community Alliance (SCA) in partnership with Southall Health Improvement Project (SHIP) and the Diabetes UK Ealing Voluntary Group is delivering the 'Communities Against Diabetes' (CAD) pilot project. Working with and complementing the services of key providers such as Diabetes UK and Ealing Public Health the CAD project has two key aims:

- 1) Improving primary prevention: by raising awareness of diabetes amongst those at risk and by utilising different methods of communicating steps to leading a healthier lifestyle, thereby reducing the risk of type 2 diabetes.
- 2) Improving early diagnosis: by increasing the availability and uptake of diabetes screening/risk assessments in community and other settings.

Community engagement and raising awareness

An important and integral part of the CAD Project is raising awareness of diabetes through effective and appropriate community engagement. Effective engagement can facilitate the communication of key messages from all of the partners involved, including Public Health Ealing and local health trainers. This complements all existing services and helps to promote healthy lifestyles through improving diets and increasing exercise levels. This can help to empower these communities to take some ownership of the information being disseminated and cascade it to workers, service users, clients, families and children. Another important aspect of the awareness-raising is to manage misperceptions about diabetes. There are certain myths and misinformation that are present within communities that need to be tackled with appropriate information and resources. Specific activities include:

- In Southall the CAD Project has visited several Gurdwaras and Mandirs (Places of Worship) and carried out diabetes outreach sessions. CAD project workers have engaged with over 500 worshippers and disseminated resources on all aspects of Diabetes.
- A communications strategy was been formulated to improve awareness of CAD in different communities through local media and community radio stations including Desi Radio and Westside Radio FM. A publicity flyer has been produced to promote the project to individuals, community groups, places of worship and health and social care professionals.
- Monthly health and wellbeing sessions have been held at a local church in Southall consisting of presentations on multiple aspects of diabetes, interactive group discussions and light gentle exercise sessions.
- Sure Start Ealing: 27 children's centres in Ealing will work with Communities against Diabetes and Public Health Ealing. So far, 5 children's centres have been engaged and will be involved in the Healthy Walks Programme and their staff members will be trained as walk leaders so that they can provide the weekly health walks themselves. The Children's Centres are keen for their staff to have educational sessions on diabetes and are engaging parents to attend these sessions.
- Estates Programme: Communities Against Diabetes is working with Catalyst Gateway Housing and Dominion Housing to take diabetes awareness into housing estates throughout Ealing.
- Health Centres: Southall Broadway Health Centre, Featherstone Road Clinic and Jubilee Gardens have agreed to host outreach/information sessions.
- Working with Diversity and Equality: CAD Project has linked up with Ealing Centre for Independent Living (ECIL) to provide diabetes awareness to staff, service users and carers in Ealing.

GP and Health Professionals Engagement

The CAD project is engaging with GPs and other health professionals. The Project leaders feel that they need the full support and backing of GPs so that they can work in parallel with CAD. It is also important that front line staff and receptionists in GP surgeries have a basic understanding and training of diabetes issues which enables them to engage with patients and signpost patients to services accordingly. Furthermore, CAD plans to raise awareness of retinal screening and podiatry services.

Primary Care: (Multi Disciplinary Team) in the Diabetes Care Pathway and Care Plan

The CAD Project is engaging with diabetes service providers to establish where the links between the services are and how patients should be signposted to other services. Furthermore, CAD hopes to ensure that each patient has their individual care plan.

Secondary Care: Hospital Admissions and After Care in the Community (Discharged Patients)

One of the aims of the CAD Project is to reduce the number of hospital admissions for patients with complications. As part of the patient's care plan, it is imperative to be aware of all the services that will be available when the patient leaves the hospital and to ensure that the appropriate information is made available to the patient, family members and carers.

Key lessons

- There is a huge appetite and willingness within all communities in the borough to get involved in this important project to combat the rise of diabetes through awareness-raising, prevention and early diagnosis.
- There needs to be ongoing support and commitment for the CAD Project. The project needs to deliver on-going services and not just "one off isolation." Sustainability is vital and the key to tackling health inequalities like diabetes in the Borough of Ealing.
- It is vital that GPs and other health professionals within the diabetes care pathway work and plan services together. A multidisciplinary approach is vital if the key messages are to be embedded and the treatment of diabetes is to be successful.
- Patients need to be heard and empowered to control their care. Patients do have the knowledge of their condition and empowering them by giving them a voice to influence service redesign is valuable.

Case Study 2:

Portsmouth Hospitals NHS Trust

Diabetes “Super Six” Model

Overview

In recent years, there has been ongoing debate in diabetes care about which individuals need to stay within secondary care and the underlying reasons for this. Portsmouth Hospitals NHS Trust Diabetes team developed the “Super Six” model, which bridges the divide between primary care clinicians and specialists, enabling primary care teams to function within an extended clinical professional domain in their community setting. In the model, the role of a diabetes specialist is redefined away from the traditional alignment of simply being a hospital-based expert. Furthermore, there is an expansion of the role’s educator component, not only that directed to people with diabetes but also for primary care clinicians.

Objectives

The diabetes team wanted to improve overall outcomes for diabetes patients. Several barriers to achieving this were identified:

- Inefficiencies in the traditional pathway (e.g. long-term follow-up for individuals with diabetes was being conducted in specialist care clinics [at significant expense], resulting in an absence of structured care plans or duplication of effort).
- Variation in the quality of the service provided in primary care and in the community setting (this was believed to be contributing to higher than expected rates of both diabetic emergency admissions and complications in the local population).

Strategy

The redesigned diabetes care pathway was developed jointly between commissioners and providers from across the healthcare community. Using existing policy and best practice guidance, it was agreed that there would be an aim of discharging 90 per cent of people with diabetes who were currently receiving follow-up secondary care in “general/complex diabetes clinics” back into primary care. Under the new alignment, diabetes care was to be delivered by dividing the team’s roles into two key areas:

1. Specialist service delivery, which comprised six defined areas of diabetes care: inpatient diabetes, antenatal diabetes, diabetic foot care, diabetic nephropathy (individuals on dialysis or with progressive decline of renal function), insulin pumps, type 1 diabetes (individuals with poor control or young people).

2. A healthcare professional educator role, which offered educational support to primary care via “virtual” access (telephone and email) and direct visits to GP practices (each practice getting two visits per year) for all other people with diabetes within the community. A consultant and a diabetes specialist nurse visited each practice, and the educational session was attended by the GPs and practice nurses.

GP engagement was recognised as being vital, and this was sought early in the process of redesigning the diabetes care pathway. A baseline assessment was undertaken by consultants and GPs, with the agreement of patients. This identified individuals with diabetes who could be discharged to primary care and those who were more appropriately retained by the specialist care team, within the Super Six clinics.

Outcomes

Since implementation of the service in November 2011, which started with 53 GP practices, the model has now extended to a total of 80 GP practices (representing 100 per cent practice coverage across two CCGs in the areas). More than 90 per cent of people with diabetes (978 individuals) deemed the service to be just as useful for carers or significant others who accompanied them. Primary care feedback has shown that 91 per cent of practices would like the service to continue and have had a high level of satisfaction; the remaining 9 per cent stated that “it was too early to comment.”

After 18 months of having this new model in place the monitoring of hard outcome measures has demonstrated encouraging results. Based on data available from the hospital business intelligence unit and a comparison of admission data from the year before the model was launched and 12 months after, there has been a reduction of episodes of diabetic ketoacidosis by 18 per cent (228 to 187), a reduction of hypoglycaemic admissions by 16 per cent (116 to 97) and a reduction of admissions with hyperglycaemic non-ketotic coma by 22 per cent (nine to seven). Local rates of myocardial infarction, amputation and strokes in individuals with diabetes have also been monitored from November 2011, and, encouragingly, they have not shown any increase. Longer-term data will be needed to draw a firmer conclusion, and it will be difficult to adequately control for all possible confounders.

The innovative model of working aimed at crystallising the role of diabetes specialists within an acute trust while using their skills and expertise within the community has also been recognised locally and nationally as an example of good practice.

This has also showcased an example of integrated care where three providers (Portsmouth Hospitals NHS Trust, Southern Health NHS Foundation Trust and Solent NHS Trust) have come together to work to one designated pathway for improvement of patient care.

Key lessons

It is clear that the basis for success lay in redefining the role of a consultant to that of a specialist who is capable, as an educator, of providing a support framework for primary care via direct or virtual means. Success has also hinged on specialists being brave enough to embrace the concept of not having to see each patient but actually supporting the concept of care being delivered, for the most part, in the community setting. The overarching lesson is that different parties need to show respect for each other's area of expertise.

No-one can deliver everything; rather, there is a need to work together to deliver good-quality care rather than operating in isolation. The achievements have relied on the strong relationships that have been built across primary and secondary care.

One of the key lessons has been in the benefits of having the same specialist team be a part of both the acute and community teams. This has helped to create a seamless bridging link and to avoid both the creation of silos and the need for conflict between different providers. This has also provided the opportunity for the acute nursing team to concentrate on delivering optimal care in the six areas while the community nursing team has concentrated on education and support for primary care.

Case Study 3:

Annual Preston Health Mela

Overview

The Lancashire Gujarat Health Users' Forum (LGHUF) was launched in 2001 to improve the health of the community by raising awareness of disease and conditions. LGHUF has organised an annual Health Mela in Preston, Lancashire since 2002 with the help of Professor Satyan Rajbhandari, a local diabetologist. The Mela has also been held annually in Bolton, Blackpool and Leyland, and more recently in Chorley, Bradford, Wales and London. The Health Mela is held on a Saturday, and is a free open day for the local community. As the name implies, the Mela (Sanskrit for gathering or fair) is intended to be a family fun event, especially for the South Asian communities. The event provides an opportunity to visit a number of health-related information stands, engage with health professionals and seek information and guidance. This raises awareness regarding various health issues including diabetes, hypertension, stroke, arthritis, coronary artery disease and cancer.

Strategy

There is a wide range of participation in the health mela to make it a significant social event. There are a number of stalls promoting healthy living from the acute hospital trust, CCG and community trust as well as social services and other health related voluntary organisations. Recently, the local rotary clubs and universities have also taken an active role in organising health melas. The University of Bolton is now hosting the 'National Forum for Health & Wellbeing', chaired by Professor Romesh Gupta to oversee health melas all over the country.

The main attraction at the mela is the free walk-in 'Health MOT (Health checks)'. These are performed by medical students and laboratory teams under the guidance of consultant physicians. People get their height, weight, blood pressure, cholesterol and glucose measured. Medical students then provide advice based upon their risk factors and lifestyle, utilising various teaching aids like cardiovascular risk calculation, diabetes risk calculation, and BMI calculations. In recent years, the health checks have added additional patient testing of HbA1c, full lipid profile, proteinuria and counselling by local NHS dietitians, diabetologists, diabetes specialists nurses and podiatrists.

This is very popular amongst people with diabetes. If any problems that require medical attention are detected, the individual is referred to his/her own GP for further investigation and treatment.

Outcomes

Every year about 1000 people attend Preston Health Mela and 200 people have full health checks. At each event, healthcare professionals diagnose several new cases of diabetes, between five and eight cases of hypertension and between six and ten cases of high cholesterol. In addition, healthcare professionals identify many people with established diabetes who have not had regular checks and make them aware of the benefit of diabetes control in preventing long term complications.

Key lessons

Health Mela are useful in:

- 1) Improving awareness and promote a healthy lifestyle within hard to reach communities regarding the range of health care services available.
- 2) Providing an opportunity to have a health assessment including blood sugar and cholesterol check and appropriate counselling.
- 3) Catering for special needs of South Asians with diabetes and guide them to the service provided by the local NHS.
- 4) Providing learning opportunities for medical students.

Case Study 4:

Apnee Sehat – South Asian Specialist Intervention Clinic (SASI)

Overview

Apnee Sehat ('Our Health') is a social enterprise established in 2005, which tailors lifestyle programmes to meet the needs of Britain's South Asian community and their mainstream services. Apnee Sehat's South Asian Specialist Intervention Clinic (SASI) is an innovative Consultant Diabetologist-led "one stop shop", incorporating clinical interventions, tailored education and lifestyle advice. Coventry has a high prevalence of social deprivation and also has a large minority ethnic population. Foleshill has a large number of South Asians, and is the most deprived ward in Coventry. Therefore, a pilot study was undertaken in a single GP practice in Foleshill utilising the SASI.

Objectives

The aim of South Asian Specialist Intervention was:

- To improve health outcomes for South Asian patients with Type 2 Diabetes, using tailored lifestyle interventions to reduce health inequalities;
- To improve the quality of life for South Asian patients with type 2 diabetes;
- To reduce HbA1c, cholesterol and blood pressure;
- To empower South Asian patients and increase their confidence in managing their condition;
- To improve patients knowledge and understanding of type 2 diabetes and related conditions.

Strategy

Apnee Sehat's SASI clinic was run by a consultant diabetologist in a single GP practice in Foleshill, Coventry, with a follow up visit after 4 months, aimed at South Asian patients with type 2 diabetes. All patients attended a "one stop clinic" where they were given written care plans and individualised targets. The strategy was to treat patients from both a clinical and lifestyle perspective in the community. Consequently, Apnee Sehat clinics were held in a local GP Practice, which is a safe and familiar surrounding for this hard-to-reach group.

Outcomes

Out of 70 South Asian patients with type 2 diabetes invited, 55 patients attended and were seen with a follow-up visit at four months.

- HbA1c improved in 77 per cent of patients, with a mean reduction of 1.3 per cent, and a reduction as great as 6.2 per cent in one patient.
- 79 per cent of patients improved on their previous blood pressure results, with a mean systolic blood pressure reduction of 14.9mmHg, and diastolic blood pressure reduction of 9.9mmHg.
- 59 per cent of patients improved on their previous total cholesterol results, with the mean result being 4.0mmol/l.
- 36 per cent of patients had a calculated cardiovascular disease risk higher than 25 per cent before the clinic. At follow up, this was reduced to only 15 per cent.
- Most patients said they had made behavioural and lifestyle changes, which they had implemented as a result of Apnee Sehat's intervention.
- Patients felt more confident and empowered to self-manage their diabetes. The average patient confidence rating of managing their condition at the start was five out of ten, which increased to eight out of ten at follow up.

Key lessons

Apnee Sehat's South Asian Specialist Intervention Clinic (SASI) are a cheap and easy-to-implement model of care to improve the care of South Asian Type 2 Diabetes patients, even in areas of social deprivation. This model can be easily replicated anywhere across the UK, and has recently been rolled out to several other areas including Birmingham and Walsall.

Case Study 5:

Diabetes UK Community Champions project

Overview

The Diabetes Community Champions project is to train people from Black, Asian and minority ethnic communities as Champions to raise awareness of diabetes and its long term complications, to signpost people to diabetes services, bridge the gap between community and healthcare settings and persuade people from these communities to have a diabetes test. Diabetes UK is aware that people from BME communities are at higher risk of developing diabetes, and also knows that people from these communities are less likely to access healthcare services. There are currently 500,000 people who have diabetes and don't know it yet and Diabetes UK believes that many of these people are from the high risk groups.

Strategy

For an organisation like Diabetes UK, it is difficult to reach all people from all communities. It was, therefore, important to train, educate and support people from different communities who have the ability to understand the different languages, lifestyles and cultures. These people are able to engage with BME communities to improve awareness about diabetes, including its signs, symptoms, risks and complications, and which interventions and treatments are available.

To facilitate this, Diabetes UK Diverse Communities Officers identify, recruit and train volunteers to deliver culturally sensitive diabetes awareness and lifestyle information within their own communities, whilst encouraging people to access their local healthcare and diabetes services. Trained champions are supported by Diabetes UK to deliver events and empower individuals in their communities to be aware of the risk factors of type 2 diabetes, consequently improving their long-term health outcomes.

The project has, to date, worked in the following boroughs in London: Croydon, Haringey, Hammersmith and Fulham, Harrow, Bexley, Newham, Lewisham, Lambeth, Southwark and Ealing. The project has worked in the following towns and cities across England through the Health and Social Volunteering Fund: Luton, Leicester, Ilford, Swindon, Birmingham, Slough, Manchester, Bradford, Sheffield, Leeds, Liverpool and Knowsley.

Community Champions – Ramadan pilot project

In 2013 Diabetes UK ran a Ramadan pilot programme drawing together expertise and good practice from across the organisation and insight from some of their African and African British volunteers to give a clear message about staying healthy during Ramadan.

Diabetes UK Community Champion Yasroon Elmi, of Somali descent, and other African and African British volunteers developed resources that could be useful to for engaging with Muslim diabetics. The resources were designed to help raise awareness of the importance of preparation and good blood glucose management during Ramadan when fasting.

Yasroon attended seven Mosques in London to deliver the key messages, in partnership with the congregation and Imams, reaching out to an average 15,000 people. The screen casts were viewed by over 2,000 people and the Ramadan factsheet was downloaded by 5,000 people. Diabetes UK achieved 75 items of coverage - a reach of 4,409,762. Yasroon was also nominated and won the Mayor of London Volunteer award for the work she achieved on the Ramadan project in November 2013.



Outcomes

Each London borough has 15 Champions who are trained and commit to organising 4 events across the project lifetime (9 months). Some events can attract over 3,000 people e.g. Mosque at prayer time. Some events, delivered in a community setting, attracted over 300 people. Community Champions present information about diabetes in the most culturally appropriate way and disseminate diabetes information.

All Champions are trained to risk assess people with diabetes. Furthermore, Champions organise an events where people can get a risk assessment to see whether they are likely to develop diabetes in the next 10 years. For example, in the Borough of Haringey, 100 people were risk assessed, 87 out of 100 were shown to be at high risk, 69% of those people went on to visit their GP to get a diabetes test where 3 people were diagnosed with Type 2 diabetes.

The Diabetes UK Community Champions Project won the 2012 NEF - The Innovation Institute Best Example of Innovation in the Voluntary Sector award.

Key lessons

- It is important to train people embedded in existing social and religious structures in BME communities. These people will continue to deliver lessons after time-limited projects have finished.

Case Study 6: Leicester Diabetes Centre and Thare Machi learning about insulin (in type 2 diabetes) project

Overview

Leicester Diabetes Centre's research, diabetes education and clinical teams, in collaboration with the charity Thare Machi, have produced an interactive DVD to help dispel common myths and misconceptions about insulin therapy and type 2 diabetes in South Asian communities. It has been produced in Gujarati, Hindi and English. The format of the DVD is based on that used by Thare Machi to disseminate health education messages in developing countries. The content of the script for the DVD was derived from findings from qualitative studies about the views and experiences of insulin therapy from the perspective of South Asian people with type 2 diabetes.

Collaborators worked together to review and fine tune the content of the DVD on an iterative basis; a process which also included the input of lay South Asian people from a local voluntary organisation. They helped to review scripts and translations, and were involved in filming. A set of resources were also developed to assist healthcare professionals such as practice nurses and healthcare assistants. These were designed to visually explain what happens in the body when someone has diabetes and a consultation script to help elicit patients concerns about insulin therapy including hypoglycaemia.

Strategy

The pilot study's work programme was delivered from April 2013 to November 2013. The DVD formed part of a multi-faceted pilot study aimed at healthcare professionals, patients and community groups to assess whether it can help to address the reluctance of people to start insulin therapy. There were three key work programmes:

Work programme 1

Training for healthcare professionals (practice nurses, GPs and healthcare assistants) from primary care.

The aim was to train up to 15 primary care healthcare professionals to support them to achieve timely insulin initiation for South Asian patients with type 2 diabetes. Healthcare professionals were trained over two half days to use the DVD and accompanying resources. Training encompassed consultation skills and addressing different beliefs of healthcare professionals and patients about insulin therapy. Feedback on the training was obtained by a researcher from healthcare professionals via telephone interviews.

Work programme 2

South Asian communities viewing of the DVD.

Qualitative studies have shown that the social and cultural context in which patients with type 2 diabetes live and work can play an important role in influencing their decision to commence insulin therapy; and this influence may be more accentuated in South Asian communities. The aim of this work programme was to recruit up to 30 participants from South Asian communities to address myths and misconceptions about insulin therapy, at a community

level. Researchers worked with community volunteers and workers, and a community pharmacy to recruit people of Bangladeshi, Pakistani and Indian origin to view the DVD in a group. Researchers commenced group viewing of the DVD in community settings and each person in the group was asked to complete a brief version of the Insulin Treatment Appraisal Scale (ITAS), whose aim is to assess perceptions of insulin therapy. Participants were also invited to volunteer some written qualitative feedback on the back of their questionnaires. After viewing the DVD and completion of questionnaires, researchers answered participants' questions about diabetes and insulin therapy.

Work programme 3

South Asian patient viewing the DVD.

The aim was to recruit up to 30 patients to find out whether an educational DVD about insulin therapy is an acceptable and useful way of addressing concerns that people with type 2 diabetes have about insulin. Eligible patients were invited by their general practice to participate in the study. Patients who consented to take part in the study were invited by the researcher to view the DVD on an individual basis at their surgery after completing the brief version of the ITAS questionnaire. As with the community work programme, patients also completed a post-viewing ITAS questionnaire and a brief questionnaire about their demographic details. After viewing the DVD the general practice arranged for patients to attend a consultation with the practice nurse, who had attended our training sessions. The practice nurse used the resources with patients to elicit their concerns about insulin therapy.

Outcomes

Work programme 1

Training for healthcare professionals (practice nurses, GPs and healthcare assistants) from primary care.

Nine healthcare professionals were recruited including practice nurses and healthcare assistants. Overall, it was very challenging to recruit healthcare professionals to attend the training sessions largely because many of the GP practices in the target area were already committed to a programme of training in diabetes clinical management.

Participants were impressed with the resources used and many thought they could be used to train staff in other care setting settings. Feedback included:

"(the) DVD is nice and simplified, it gets the message across"

"(the) DVD would be useful to use as an education tool to educate the HCP. Overall knowledge in diabetes is very poor, so it is important to improve knowledge for different HCPs. People take information in better if it is presented in a pictorial way."



Work programme 2

South Asian communities viewing of the DVD.

The data from the ITAS questionnaires is currently being analysed and preliminary analysis suggests that the DVD had a positive impact on changing people's perceptions of the insulin therapy. A total of 45 people were recruited. The community volunteers and workers, as well as pharmacy staff, were trusted members of South Asian communities and recruiting participants through them helped to exceed the recruitment target. Additionally, community interest in the DVD snowballed as some participants who had viewed the DVD as part of a group, contacted the research team to show the DVD at a community health fair and a patient participation group event.

The researchers received very positive qualitative feedback from many participants, particularly from people who had type 2 diabetes and had been asked by their GP to commence insulin therapy but were reluctant to do so. Feedback included: "the DVD has taken away fear of consequences of using insulin" and "Watching the DVD makes me clear that insulin is beneficial rather than scary or harmful."

Work programme 3

South Asian patient's viewing of the DVD

The researchers recruited 3 patients despite the commitment and interest of the 9 healthcare professionals who attended the training to use the DVD and resources with patients at their practices. There are many reasons for the lack of patient recruitment to this study; one of the most commonly cited being patients' reluctance to participate in research studies. The preliminary analysis of the qualitative feedback received from interviews with the 3 patients suggests that the DVD dispelled myths about 'scary' injections and reinforced the message about the necessity of insulin.

Key lessons

- The most successful way of engaging and recruiting South Asian people in this study was by working with stakeholders in the community. They were committed to helping people in their communities by working with the research team to achieve the study's objectives.
 - Viewing a DVD in the community rather than in a clinical setting may have helped some people to feel more at ease about exploring concerns and questions that they had about diabetes and insulin therapy.
 - Group-based viewing of the DVD enabled participants to interpret and validate existing levels of diabetes knowledge.
 - Feedback from healthcare professionals suggests that consultation skills on how to elicit and address patient beliefs about insulin are also needed alongside clinical diabetes management skills.
 - Preliminary feedback from the healthcare professionals who used the resources found they were helpful to visually explain what happens in the body.
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Case Study 7: Portsmouth Hospitals NHS Trust Adolescent and Young People Transition Service - STYLE (Safe Transition to Young adult Life)

Overview

The Portsmouth Hospitals NHS Trust young person diabetes service has been re-structured through a collection of initiatives creating a defined transitional process. Transitioning from paediatric to adult diabetes services can be a notoriously difficult process due to change of staffing combined with the typical challenging nature of engaging young people. This niche group cannot be managed in a traditional didactic manner but requires modern thinking and strategies in keeping with contemporary lifestyles.

Objectives

The aim of re-structuring was to develop a solid, cohesive, modernised, and dedicated multi-professional team to support young people in a way that is acceptable to them and their lifestyles. The aim of the project was to help young people develop confidence in using services by establishing good relationships and taking increased responsibility for their health, as failure to do so may set patterns for long term poor use of services.

While encouraging freedom and honesty in lifestyle choices, the healthcare practitioner endeavours to remain non-judgemental to risk-taking behaviours but supports the young person to understand how to approach these inevitable risks. Parent and child conflicts relating to diabetes management are common. In an attempt to reduce such frictions, the new service also aimed to involve the parent in the transition process.

The project hoped to improve patient satisfaction, reduce diabetic ketoacidosis admissions, reduce 'did not attend' rates and ensure that young people transitioning into adulthood experienced fewer long term complications.

Strategy

Patient engagement was an essential aspect of developing the strategy. Patients were invited to contribute via social media, focus groups and through direct questioning. Ideas presented included:

- (a) In conjunction with the paediatric team a defined transition process was established which flowed from the paediatric team introducing and 'handing over' the young person to the adult team. Service differences were highlighted and welcome packs provided.
- (b) The next follow up involved a group education session which both the parent and young person attend, but in separate rooms (to allow freedom of speech) to discuss risky lifestyle behaviours and how to remain safe.
- (c) Further one to one follow ups are guided by the young person as they are provided with a lifestyle sheet from which they choose which topics they wish to discuss.
- (d) Direct email, text and ad hoc appointments allow easier access to the team.
- (e) An IT-based routine screening tracker highlighting when tests are due helping to monitor up-take.
- (f) Clinics have been set up in a local university campus to reduce travel and cost for those individuals.
- (g) New education techniques such as simulations and medical models to help engage young people.



Outcomes

- Reduced 'did not show' rates to 10-15 per cent (from 40-50 per cent)
- Reduced diabetes ketoacidosis admissions by 11 per cent
- Patient satisfaction surveys have shown highly positive responses from both young people and parents

Key lessons

Empowering patients to take responsibility for their own care can improve outcomes. The transition from adolescent to adult diabetes services can be difficult, but by engaging with the service users and their families, in different ways, it is possible to understand how they want their service to operate. This translates into improved satisfaction rates, fewer complications and fewer admissions. This service is mainly directed at patients with type 1 diabetes. However, the main lesson from the case study around managing the transition between adolescence and adulthood can also be applied to type 2 diabetes services.

Case Study 8:

Glasgow Minority Ethnic Long-Term Medicines Service (MELTS)

Overview

The Glasgow Minority Ethnic Long-Term Medicines Service (MELTS) was developed in recognition that the existing medicines review service in Glasgow was not meeting the needs of the South Asian population. Given that South Asian people have a higher incidence of diabetes and reduced access to healthcare services, a medication review clinic for Urdu-speaking patients was developed. The project was developed by Dr Richard Lowrie and Professor Kate O'Donnell.

Strategy

The development of MELTS was carried out in several stages. First, South Asian patients with diabetes were contacted in their spoken language of Urdu and invited to attend the clinic. Second, outreach clinics were established in public areas to increase attendance. For example, clinics were held in a mosque, a Hindu elderly centre, a Sikh elderly centre and other voluntary centres. Third, clinics were also held in a community pharmacy in an area with a large Asian population.

Patients can refer themselves to the clinics, or be referred by family members and healthcare professionals. While at the clinic, patients receive a full medication review in a language that they can understand and, if necessary, changes are made to optimise their regime. Significantly, patients can also be referred on to other services including mainstream healthcare, English speaking classes, welfare and social care.

Outcomes

Demographic, clinical and prescribing data for 169 individuals was collected during a medication review service conducted between 2003 and 2010 in a NHS Glasgow general practice. Most patients were Pakistani, with a mean age of 61. Three quarters were identified from the general practice diabetic list. Each patient received an average of nearly 5 face-to-face consultations; 65 patients had nearly 3 telephone consultations. The mean length of time in the service was 19 months. There were 27 joint consultations, where another healthcare professional or family member was part of the review, and 112 linked-in consultations, where another healthcare professional or family member was consulted after the review.

154 onward referrals were made to 13 different departments within the health and social care team. There were 379 drugs prescribed in 13 different drug classes, of which nearly three quarters were prescribed via the GP and the rest via the pharmacist prescribing independently.

The service allowed engagement with a relatively deprived South Asian population over a seven year period. There were reductions in the clinical surrogate markers (HbA1C, lipids and blood pressure) from pre-to-post pharmacist intervention which were statistically significant apart from HbA1c in patients prescribed a drug by the pharmacist which related directly to that surrogate marker.

The service has been extended to include all ethnic minorities including people from African-Caribbean backgrounds. Asylum seekers can also receive advice and support from the clinics.

Key lessons

- It is feasible for pharmacists to become integrated as part of the diabetes care team in a general practice and manage high-risk South Asian patients.
- Medicines management is an essential service for allowing patients to better manage their own health.
- Services based in the community can be crucial in reaching out to people who would not otherwise engage with traditional healthcare services.

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Diabetes in BME Communities

Raising awareness, improving outcomes and sharing best practice



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