

A Diabetes Scotland initiative: Diabetes and Me – diabetes support through community engagement

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Article points

1. Not only are South Asian people disproportionately affected by type 2 diabetes, they may also have to overcome other barriers to reduce their diabetes risk.
2. The aim of Diabetes and Me is to support and empower people from South Asian communities living in Glasgow to participate in the self-management of their diabetes and associated long-term conditions.
3. Diabetes and Me continues to encourage community engagement with the ultimate aim to reduce incidence of diabetes and diabetes-related complication by increasing the knowledge-base of the South Asian community.

Key words

- Community engagement
- Diabetes
- Self-management
- South Asian

Authors

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The Diabetes and Me project was initiated in 2012 to address Diabetes Scotland's commitment to support people from Black, Asian and other Minority Ethnic (BAME) groups to live well with diabetes. The project was the first of its kind for Diabetes Scotland, using three different models of community engagement with South Asian communities to raise public awareness on diabetes, provide focussed and tailored support sessions led by trained volunteers, and work collaboratively with local service providers. The project reached over 3000 people in 24 months and, in 2014, Diabetes and Me won the Quality in Care Diabetes award for the best initiative to support quality of care in "hard-to-reach" groups. This paper describes the models of community engagement used to provide diabetes support for South Asians living in Glasgow and describes key outcomes and practical messages for future community engagement among BAME groups.

South Asians comprise around 4% of the UK population (Macaden, 2010) and are at higher risk of developing type 2 diabetes than White ethnic groups, with the condition also tending to present at an earlier age (NHS Scotland, 2012). In Scotland, 67% of the minority ethnic population is Asian (The Scottish Government, 2011), and the Scottish Diabetes Survey 2014 indicates that there are over 8000 people of South Asian origin living with either type 1 or type 2 diabetes (Scottish Diabetes Survey Monitoring Group, 2014). This number may be higher given that there are over 51 000 people with diabetes whose ethnicity is not currently recorded (Diabetes Scotland, 2014). The majority of Scotland's Asian population reside in Glasgow ($n=47\ 972$; which is approximately 8% of the city's population [National Records of Scotland, 2015]).

Research has shown that people with an Indian or Pakistani origin with type 2 diabetes are more likely to have suboptimal glycaemic control than the White Scottish population (Mather et al, 1998), which leads to an increased risk of renal

and cardiovascular complications compared to other ethnic groups (Burden et al, 1992; NHS Scotland, 2012). New research has also highlighted the need for South Asians to exercise longer than white Europeans to achieve the same levels of fitness and reduce their risk of diabetes (Diabetes Scotland, 2014).

Barriers to improving health and wellbeing

Not only are South Asian people disproportionately affected by type 2 diabetes, they may also have to overcome other barriers to reduce their diabetes risk. Access to care and education can be more problematic for these communities, often due to services that do not meet linguistic and cultural needs. This can contribute to incomplete knowledge about treatments and a reduced perception of the seriousness of the condition. Diabetes is still seen as a stigma (Singh et al, 2012), and, in Diabetes Scotland's experience of working with communities, talking about it openly has been difficult for people.

The Scottish Government has acknowledged health inequalities in the Diabetes Improvement Plan for Scotland 2014 (Diabetes Scotland, 2014). It cites health inequalities as the greatest challenge for public health and highlights the need to reduce the impact of deprivation, ethnicity and disadvantage on diabetes care outcomes. In spite of the resources and efforts invested in diabetes services, there are still significant gaps in providing support to people from Black, Asian and other Minority Ethnic (BAME) communities who are regarded as “hard-to-reach” or “easily ignored” groups to self manage and live well with their diabetes. Implementing cost-effective interventions that address health inequalities in minority ethnic groups is still a challenge (Scottish Government and Alliance Scotland, 2008).

Diabetes education interventions aimed at patient empowerment and self-management do not always factor in the socio-cultural and religious beliefs and practices of minority ethnic groups (Hawthorne et al, 2010). Previous intervention strategies implemented in the South Asian community have included using trained South Asian link workers to offer culturally appropriate diabetes advice (Scottish Government and Alliance Scotland, 2008) and South Asian dietitians who made home visits to offer culturally appropriate dietary advice (Douglas et al, 2011). Both interventions had very modest outcomes and offered suggestions to provide culturally sensitive diabetes education, such as using bilingual health care staff; emphasise cultural competence in the health professionals’ curriculum; train and network with religious leaders to address some of the barriers to education; and run drop-in centres or satellite clinics (Macaden and Clarke, 2015).

Researchers of the PODOSA (Prevention of Diabetes and Obesity among South Asians) study have reported that the most successful recruitment strategies for their study were partnerships with local South Asian organisations and individuals, and referrals by word of mouth from South Asian participants (Douglas et al, 2011).

Diabetes and Me: The community engagement framework

The aim of Diabetes and Me was to support and empower people from South Asian communities

living in Glasgow to participate in the self-management of their diabetes and associated long-term conditions. The project methodology is rooted in the values laid out in ‘Gaun Yersel!’ – the self-management strategy for long-term conditions in Scotland (Scottish Government and Alliance Scotland, 2008).

The Diabetes and Me project embarked on a series of stakeholder consultations with NHS Greater Glasgow & Clyde and over 41 organisations in Glasgow (e.g. health improvement teams, community centres, religious institutions, youth organisations, local businesses and South Asian community members, leaders and volunteers) to gain an understanding of what would promote meaningful engagement and self-management of diabetes among South Asians living in Glasgow. These meetings were set up at the start of the project but continued to take place throughout as we developed both the methodology and plans for implementation. As a result of the stakeholder consultations, a three-pronged framework was developed to maximise community engagement through the Diabetes and Me project (see *Figure 1*).

Impact of the community engagement framework

Table 1 (on page 83) presents a description of the components of Diabetes and Me that were used in the three-pronged approach. The wider-reaching impact of the programme is described below and grouped into major themes.

Peer support

Peer support and role models build confidence and help people to explore healthy lifestyles. Some groups have grown into peer-support teams, where participants support each other and discuss their goals and progress. Two of the groups with a total of 36 participants pilot-tested walking groups. Both groups continue to be active beyond the project, providing each other encouragement to remain active. Two full-time community support workers were recruited to facilitate community engagement, and 29 volunteers from within the South Asian communities were trained to raise awareness and share accurate information about diabetes and the importance of self management.

“Self management is the successful outcome of the person and all appropriate individuals and services working together to support him or her to deal with the very real implications of living the rest of their life with one or more long term condition.”

“Gaun Yersel!”

Page points

1. In spite of the resources and efforts invested in diabetes services, there are still significant gaps in providing support to people from Black, Asian and other Minority Ethnic communities who are regarded as “hard-to-reach” or “easily ignored” groups to self manage and live well with their diabetes.
2. The aim of Diabetes and Me was to support and empower people from South Asian communities living in Glasgow to participate in the self-management of their diabetes and associated long-term conditions.
3. As a result of the stakeholder consultations, a three-pronged framework was developed to maximise community engagement in the Diabetes and Me project.



Figure 1. The three-pronged framework for community engagement as part of the Diabetes and Me programme (Chinikum=low sugar).

Self-management

Project evaluation revealed that many users of the framework were beginning to become more aware of the seriousness of the condition and moving away from the idea that diabetes care was their doctor’s responsibility. As a result, many of our group participants were initiating and maintaining healthy lifestyle changes.

The concept of self-management did not seem to be familiar among South Asians in this project. The interpretation of self-management differs widely between lay people and practitioners (Sadler et al, 2014), and within the population of the community engagement programme, the term “self-management” seemed to hold negative connotations, such as, “doing it alone” and “it’s your fault and your responsibility”. From speaking to participants, what also hindered motivation to better self-manage was that improvements or changes in health were mostly intangible and did not bring on immediate results. These findings were very similar to those reported by Macaden (2010).

Through involvement in the project, the awareness of the importance of self-management has been raised. Diabetes Scotland is increasingly being accepted as a trusted provider of information and support, as well as a source of culturally appropriate support.

Healthcare professionals

People trust healthcare professionals to provide

personalised information. However, community members were not clear on what services they were eligible for. Participants confirmed the need to have a support network outside the NHS that can help them manage the day-to-day challenges of living with diabetes.

We found that most community members preferred one-to-one interaction accompanied by information material in an accessible language and format. For many South Asian people, there is a fear that admitting to having the condition could prompt blame or embarrassment to a particular community, family or individual.

Key practical messages for community engagement

This is for organisations who would like to pursue community engagement initiatives.

Improving motivation for self-management

- Understanding what motivates people can increase the likelihood that they will sustain behaviour changes. Motivation could be a desire for more knowledge, better health, less pain or particular religious beliefs.
- Creating the right environment is key to improving motivation. South Asian communities are closely knit and enjoy learning and taking part in new activities in a familiar setting surrounded by family or friends. This naturally lends to peer support

Table 1. An analysis of the various components of community engagement for diabetes support.

| Strategy | n | Participant profile | Venue | Description | Strengths | Limitations |
|--|-------|--|--|---|---|---|
| 1. Raising public awareness at local community venues | | | | | | |
| Diabetes literacy | 2600 | | Various – the Glasgow Mela, schools and community halls. | Sessions delivered by bilingual community support workers and 29 volunteers. Resources made available in English, Urdu, Punjabi and Hindi. | Reached a wide audience and improved visibility of Diabetes Scotland and community connections. | Difficulties with follow-up. |
| Diabetes risk assessments | 133 | General South Asian population, over the age of 16. Undiagnosed with type 2 diabetes. | Various – as above. | Performed by volunteers trained in diabetes risk assessment. One-to-one confidential chats about the risks of developing type 2 diabetes and recommended actions to lower risk. | Increased awareness of personal risk of type 2 diabetes. Those at increased risk were referred to their GP for further checks and information on reducing risk. Follow-up via email. | |
| Radio Awaz – the Healthy Morning show | 2000+ | South Asian communities listening live in Scotland and the UK. People in South Asian countries listening via podcasts. | On air. | A series of interviews led by the presenter of the Healthy Morning show on a radio station that has one of the highest number of listeners of South Asian origin in Scotland. Covered a range of topics on diabetes and living well. | Ability to reach wide audience. Health information presented in an informal conversation style, with Diabetes Scotland being able to contribute in a South Asian language. Opportunities for listeners to call in with questions. | Difficulties with follow-up. |
| 2. Chinikum* support groups | 120 | Mostly women over the age of 55 years either living with diabetes or caring for someone with diabetes. | Elderly care centres for South Asian community members. | Support delivered by trained bilingual VGLs. They were supported with diabetes literacy resources, which included information on diabetes experts and local resources such as yoga instructors, eye checks and mental health support. | Developed a series of tailor-made support sessions on diabetes self-management. Practical workshops on cooking, physical activity and healthy goal setting. Walking clubs evolved from some groups. | VGLs expressed their lack of confidence in leading discussions on diabetes due to the complex nature of the condition. There was a lack of engagement by some participants in group sessions as the VGLs were not diabetes experts; therefore, supervisory support was required by VGLs to ensure content was delivered accurately. |
| 3. Collaboration for community engagement | 150 | People with diabetes, carers and family members. Those at risk of type 2 diabetes from South Asian communities. | Various (e.g. local libraries, religious venues, community halls). | An opportunity to chat to experts in diabetes and related health conditions (including pharmacists, podiatrists and dietitians) within a community setting. | Advocacy and playing host to facilitate collaboration with 10 local organisations. Facilitated quick and direct referrals as required. | Time and resource constraints for Diabetes Scotland and participating organisations and healthcare professionals. |

*Low sugar.

n=number of people; VGL=volunteer group leader.

structures being formed around diabetes management and care. Making changes as a group can be less daunting than individually (e.g. walking groups).

Communicating information

A range of approaches need to be used to communicate information in a way that resonates with the family, cultural, social and religious dynamics of the South Asian community.

- Positive messages about managing the

condition and self-management, including support and motivation, which encourages open communication.

- Models of diabetes care relying on individual compliance or over-dependence on healthcare professionals often leads to poor diabetes outcomes.
- An available support network outside the NHS that can help individuals manage the day-to-day challenges of living with diabetes.
- Information needs to be followed up with

Page points

1. Being visible in the community helps demonstrate commitment to the cause or task at hand, and also gives the opportunity for people to approach the service of their own accord.
2. A community health intervention cannot function in isolation from other services and providers, and can benefit greatly from specialist input and resources.
3. Evaluating the impact of community engagement and finding methods for gaining quantitative feedback from people on their improved self-management is challenging.

practical advice and support.

- It is important to remember that diabetes can impact some family members disproportionately. Often carer duties, and the responsibility of being the carer within the family, falls on women within the South Asian household.

Community engagement Approaching communities

Directly approaching a community group to seek their buy-in for one's work can be a difficult way to introduce community engagement. Being visible in the community (e.g. being involved in community festivals and events) helps demonstrate commitment to the cause or task at hand, and also gives the opportunity for people to approach the service of their own accord.

Building trust and setting expectations

Trust can be built by clearly communicating your role and commitment at the very outset, and by setting expectations on what can be realistically offered. This can result in your services being recognised and recommended to the wider community by word of mouth and through community networks.

Working in partnership with specialist input and local organisations

A community health intervention cannot function in isolation from other services and providers, and can benefit greatly from specialist input and resources. Entering into meaningful partnerships that are of mutual benefit to the organisations and individuals involved can greatly strengthen the message. Information sharing and honest communication are vital for a partnership to succeed. Also working in partnership with community leaders, local businesses and other organisations can help to widen the reach and reputation of the activity or project undertaken.

The role of healthcare professionals in community engagement

Communication with healthcare professionals can be difficult for some individuals and groups. Healthcare professionals delivering community services and attending events can help to

connect with community members and interact at a local, more informal level.

Building on community assets

The South Asian communities' assets are strong and influential. Whether it be family, community networks, religion, festivals or events, building on these assets and using them as vehicles for supporting diabetes self-management can bring in sustainable benefits to the community at large.

There is evidence from the literature to support the use of non-professionals to lead diabetes self-management peer-support groups (Fisher et al, 2012).

Discussion

Evaluating the impact of community engagement by quantitative means is challenging, especially when the aim is to measure improvement with self-management. With this not being a research project, the focus has been to develop a model to support self-management of diabetes among the South Asian community through community engagement. Feedback was mostly obtained informally collecting data during activities such as walking groups and cookery demonstrations. The focus of feedback was primarily opinion based. The project had no access to clinical data and did not record waist circumference, BMI or blood pressure as we were keen to engage with people through community development, rather than using the traditional clinical approach, to promote self management. Emphasis was, therefore, on confidence building, empowerment and developing peer support structures that would lead to more self-supported diabetes care, and, in time, translate to better clinical outcomes for diabetes.

Future projects

Based on the success of the Diabetes and Me project, Diabetes Scotland secured a third grant from Health and Social Care ALLIANCE Scotland to develop the community asset-based approach to supported self-management. Designing family-centred diabetes education and services for South Asians is becoming an increasingly popular recommendation in recent years given the centrality of the family unit

within the South Asian culture and the genetic predisposition that this ethnic group has towards diabetes (Macaden and Clarke, 2015). The new project, Chinikum* At Home, is based on the premise that a family-centred model of diabetes support may be effective among people of South Asian origin (Alliance Scotland, 2016). A new project has piloted a culturally sensitive, family-focused model of intensive diabetes support working with 16 families in the Greater Glasgow area. The project aims to ensure that those at high-risk of complications associated with diabetes have increased knowledge and skills through a family-focussed approach. Feedback from participants and initial evaluation results show that the pilot has been successful in achieving these outcomes. Findings from this work are being drafted for publication. For more information on the results and findings of the Chinikum at Home project, contact Diabetes Scotland on 0141 245 6380 or scotland@diabetes.org.uk.

Conclusion

Diabetes and Me continues to encourage community engagement with the ultimate aim to promote self management and prevent diabetes-related complications in minority ethnic groups. It is important that some of the key messages in this paper are given attention whilst planning community engagement initiatives for non-communicable and lifestyle-related conditions, for minority ethnic groups to engage positively with the services offered. ■

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Alliance Scotland (2016) *Chinikum Families Project – Diabetes Scotland*. Health and Social Care Alliance Scotland, Glasgow. Available at: <http://bit.ly/1U74LWD> (accessed 15.03.16)

Burden AC, McNally PG, Feehally J, Walls J (1992) Increased incidence of end-stage renal failure secondary to diabetes mellitus in Asian ethnic groups in the United Kingdom. *Diabet Med* **9**: 641–5

Diabetes Scotland (2014) *Diabetes Improvement Plan*. Diabetes in Scotland, Edinburgh. Available at: http://diabetesinscotland.org.uk/Publications/Diabetes_Improvement_Plan_2014.pdf

*low sugar.

(accessed 11.03.16)

Douglas A, Bhopal RS, Bhopal R et al (2011) Recruiting South Asians to a lifestyle intervention trial: experiences and lessons from PODOSA (Prevention of Diabetes & Obesity in South Asians). *Trials* **12**: 220

Fisher EB, Boothroyd RI, Coufal MM et al (2012) Peer support for self-management of diabetes improved outcomes in international settings. *Health Affairs (Project Hope)* **31**: 130–9

Hawthorne K, Robles Y, Cannings-John R, Edwards AG (2010) Culturally appropriate health education for type 2 diabetes in ethnic minority groups: a systematic and narrative review of randomized controlled trials. *Diabet Med* **27**: 613–23

Macaden LC (2010) The influence of locus control on risk perception in older South Asian people with type 2 diabetes in the UK. *J Nurs Healthc Chronic Illn* **2**: 144–52

Macaden L, Clarke CL (2015) Model of diabetes management: Have we got it right for South Asians in the UK? *Journal of Diabetes Nursing* **19**: 183–9

Mather HM, Chaturvedi N, Fuller JH (1998) Mortality and morbidity from diabetes in South Asians and Europeans: 11 year follow-up of the Southall Diabetes Survey, London, UK. *Diabet Med* **15**: 53–9

National Records of Scotland (2015) *Scotland's Census 2011 – General Report*. NRS Scotland, Edinburgh. Available at: <http://www.scotlandscensus.gov.uk> (accessed 11.03.16)

NHS Scotland (2012) *Scottish Diabetes Survey*. NHS Scotland, Edinburgh. Available at: <http://www.diabetesinscotland.org.uk/publications/sds%202012.pdf> (accessed 11.03.16)

Sadler E, Wolfe CD, McKeivitt C (2014) Lay and health care professional understandings of self-management: A systematic review and narrative synthesis. *SAGE Open Medicine* **2**: 1–18

Scottish Diabetes Survey Monitoring Group (2014) *Scottish Diabetes Survey 2014*. Diabetes in Scotland, Edinburgh. Available at: <http://www.diabetesinscotland.org.uk/Publications/SDS2014.pdf> (accessed 11.03.16)

Scottish Government and Alliance Scotland (2008) *“GauN Yersell!” The Self Management Strategy for long term conditions in Scotland*. The Scottish Government, Edinburgh. Available at: <http://www.gov.scot/Resource/0042/00422988.pdf> (accessed 14.03.16)

Singh H, Cinnirella M, Bradley C (2012) Support systems for and barriers to diabetes management in South Asians and Whites in the UK: qualitative study of patients' perspectives. *BMJ Open* **2**: e001459

The Scottish Government (2011) *Summary: Ethnic Group Demographics*. The Scottish Government, Edinburgh. Available at: <http://www.gov.scot/Topics/People/Equality/Equalities/DataGrid/Ethnicity/EthPopMig> (accessed 11.03.16)

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