

DIABETES AND ME PROJECT SUMMARY

The Diabetes and Me project was funded by the Health and Social Care Alliance Scotland (the ALLIANCE, formerly LTCAS) from 2010 to 2012. The project is referenced in the Scottish Government Diabetes National Action Plan, and is part of the charity's commitment to communicating diabetes health messages to people from Black, Asian and other minority ethnic groups.

The aim of the project 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 had a particular focus on engaging with men and women from South Asian origin, over the age of 45, and living in Glasgow. This age group is important to us because of the high prevalence of diabetes, plus many are caring for a family member with diabetes.

The first year of the Diabetes and Me project focused on consulting with NHS Greater Glasgow & Clyde and community organisations, identifying groups and individuals interested in participating in the project, recruiting volunteers and setting up 6 diabetes self-management support groups called *Chinikum* groups. *Chinikum* means 'less sugar' in Hindi and Urdu.

In its second year, the project continued to widen its reach and engage with and consult more stakeholders and connect with more community members. The consultations aimed to gain an understanding of what those living with diabetes need to become

more engaged in their management of the condition, and to use this learning to design project activities that support and meet this need.

During 2012 we consulted with over 41 organisations in Glasgow, ranging from health improvement organisations, community centres, religious institutions, youth organisations and local businesses.

We also:

- Provided guided self management and support to **120** *Chinikum* participant
- Recruited and trained **29** volunteers to support and sustain activities within the South Asian community in Glasgow
- Reached over **2,000** people with key messages about diabetes and self management with information material in English, Urdu, Punjabi and Hindi
- Delivered events and activities in partnership with **8** organisations including NHSGG&C (South Sector), Royal Institute of the Blind (RNIB) and Walking Towards Better Health project (ALLIANCE)
- Produced new Self Management resources and tools which are available in South Asian languages
- Conducted diabetes risk assessments at community events and offered 1:1 lifestyle advice to **133** people looking to reduce their risk of diabetes
- Delivered **4** healthy cooking demonstrations with a Community Specialist Dietitian
- Successfully pilot tested **2** walk groups with **36** participants. Both groups continue to be active beyond the project, by providing peer support and encouragement to walk more

Year two of the Diabetes and Me project has achieved the following outcomes:

- Increased understanding of how South Asian communities relate to the concept of self-management
- Increased understanding of how to effectively support the target group to begin and sustain their self management journey
- Increased availability of appropriate tools, methods and a suite of activities that were designed and piloted together with the target group
- Improved understanding of diabetes within the target group on how to look after themselves on a daily basis, manage associated risks, and access support
- Increased trust within the communities for the work of Diabetes UK Scotland, leading to an increased number of requests for awareness raising events and self-management support
- Improved capacity within Diabetes UK Scotland to support people from South Asian communities living with diabetes
- Increased understanding and experience of how to work in partnership by linking with relevant public and voluntary organisations to deliver joint health promotion and prevention activities.

What's next?

In 2013 the project will focus on:

- Reaching more people from BAME communities with Diabetes UK core information and campaigns
- Reaching more people who are at high risk and newly diagnosed, and establishing a coordinated approach to follow-up and support. To trial two new ways of community engagement and support, learning from the experiences of the previous years' work, PODOSA and SAAC
- Increasing the number of volunteers from diverse BAME groups who are trained, engaged, and help us plan our work

The learning we hope to get from this work:

- Better understanding of what a high quality self management programme for South Asian adults need to include
- Better understanding of the impact of diabetes risk assessments on high-risk communities
- Better understanding of the Patient Held Summary and www.mydiabetesmyway.scot.nhs.uk and usage among BAME communities



Below is a list of learning and suggestions that are based on the experience gained in Year 2 of the Diabetes and Me project

□ **There is no one-size-fits all approach;**

The project developed and re-shaped as it progressed through the year as we continued to interact and work together with communities and individuals living with diabetes. Several adjustments were made to the initial project plan as we got people involved in the design and development of self-management activities. We believe this made the activities more appropriate and accessible.



**WHAT
WE'VE
LEARNT**

ENGAGING COMMUNITIES

□ **Approaching communities**

Directly approaching a community group to seek their buy-in for your work is not the most recommended way of introducing yourself to a group of people. Being visible in the community by getting involved in community festivals and events that are important to them helps demonstrate your organisation's commitment to the cause/task. This also gives the opportunity for people to approach you of their own accord. Seeking out respected members of the community and gaining their buy-in often results in your organisation being introduced to community networks and further contacts.

□ **Building trust and setting expectations**

Trust can be built by clearly communicating your role and commitment at the very onset, and by setting expectations about how and what you can offer. This will invite participation and interest, and can result in your services being recognised and recommended to the wider community by word of mouth and through community networks.

□ **Communicating effectively**

We found that most community members preferred one-to-one face to face interaction accompanied by information material in a language and format that is accessible to them. For many, diabetes is a private battle they are grappling with, so talking about it openly is difficult. There is also a fear that admitting to the condition could prompt blame or embarrassment to a particular community, family or individual. Positive messages about managing the condition and that self-management is about support and motivation, encourages open communication.

□ **Involving individuals**

Giving group members small tasks/roles within the group can give a sense of purpose, ownership, and encourage leadership and confidence. It can also make the sessions more engaging. Treating people as individuals – and not only as part of a very large community whose characteristics, culture and beliefs are varied – helps make the connection more personal and meaningful.

□ **Empowering volunteers**

Supporting volunteers to take healthy lifestyle messages and self-management activities into their communities empowers volunteers, increases reach and builds in sustainability into an intervention.

PROMOTING SELF-MANAGEMENT

□ **Making sense of the condition**

People are more likely to engage in activities if they understand how their general health and condition will benefit from it. Many people we engaged with have been living with Type 2 diabetes for years, but there are huge gaps in their understanding of the condition and support available.

There are also many myths and misconceptions of the disease and treatments. Providing accurate information in an accessible format and language is an important first step.

□ **Understanding need**

People from South Asian communities feel the need to have a support network outside (and in addition to) the NHS that can help them manage the day-to-day challenges of living with the condition. Carers and Service Providers need information and support to be able to effectively care for their family/friend/service user living with diabetes.

□ **The role of health care professionals**

People trust health care professionals to provide personalised information. However, there are gaps in the communities' understanding of what services they are entitled to and what support they should be receiving. Communication with healthcare professionals can be difficult for some individuals / groups. Linking up with healthcare professionals to deliver community services and events can help HCPs as well as community members connect and interact better at a local informal level.

□ **Appropriate messages**

Some healthy lifestyle guidelines can seem unachievable or confusing to people living with diabetes. Promoting the message that health benefits can be reaped by making small changes to eating habits, exercise and keeping a diary of your medication and progress is a much more accessible message.

MOTIVATION TO CHANGE BEHAVIOUR

□ **Understanding what motivates people**

Whether it is more knowledge, religious belief, better health or less pain, finding out what motivates a person or a group - and responding to that - increases the likelihood that they will sustain behaviour changes. Activities should be flexible enough to adapt to how members feel on the day. It is important to remember that people may be at different stages in their self-management cycle.

□ **Creating the right environment**

South Asian communities are closely knit and prefer to learn and undertake new activities in a familiar setting surrounded by family or friends. This naturally lends its way to peer support structures being formed around diabetes management and care. Making changes together makes the process feel less daunting.

□ **Providing practical support and goal setting**

Information provision alone is not sufficient to encourage self management, but works well if coupled with support activities that will help people take the first step in changing health behaviour. Activities focussed on healthy eating and keeping active were popular among the people we worked with. Setting goals and encouraging participants to notice differences to how they feel increases confidence and motivates them to keep at it or do more. Piloting different approaches can help to uncover what works best for the group and individuals within it.

WORKING IN PARTNERSHIP

□ **Widening reach**

Working in partnership with community leaders, religious institutions, third sector organisations, local businesses and the NHS helps widen the reach and reputability of the activity/project undertaken. It also helps to plan and get access to the most appropriate method of engaging with communities.

□ **Benefiting from specialist input and resources**

A community health intervention cannot function in isolation from other services and providers, and can benefit greatly from specialist input and resources. This can be tapped by entering into meaningful partnerships that are of mutual benefit to the organisations and individuals involved. Information sharing and honest communication are vital for a partnership to succeed.

□ **Building on community assets**

The South Asian communities' assets are strong and influential and are what binds the communities together. Whether it be family, word-of-mouth network, religion, festivals, events, menus and habits, building on these assets and using them as vehicles for supported diabetes self management can bring in sustainable benefits to the community at large.

□ **Involving and engaging the donor/funder**

The project hugely benefitted from the ALLIANCE approach of providing continuous support and allowing us to be flexible in implementing our project. Keeping the funder informed and involved helped the project to be responsive to the needs and trends on the ground while sharing experiences and lessons learnt on a regular basis.

EVALUATION

□ **Setting a methodology**

Evaluating the impact of community engagement work and finding methods for gaining quantitative feedback from people on their improved self management is challenging. Some people do not wish to share personal information; group dynamics can impact on participatory evaluation methods; it is often difficult to maintain consistent interaction with some participants; and having a short-term funded project hinders the ability to realistically monitor health change behaviour.

□ **Using different techniques to collect data and feedback**

There is no one form/tool that fits all, and organisations should involve researchers and the community in identifying creative and suitable methods of capturing and documenting feedback on a regular basis, to give qualitative examples of changes across a group. When assessing the impact of information material and project activities and relating it to any changes in behaviour or health, it is important to consider it in conjunction with other ongoing support available and accessed by the individual or group.

□ **Communicating findings to the NHS and policy makers**

Robust evaluation and communicating it effectively can help increase the impact of the project work and can also influence design and delivery of patient-centred care. Participatory evaluation with the community can provide an insight into what individuals with diabetes regard as barriers and facilitators of their self-management, and feed into what health professionals, policy makers and researchers currently deliver and provide.

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