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SADEE SMILE EVALUATION – FINAL REPORT

An evaluation of the South Asian Diabetes Education, Empowerment and Self-Management in Leeds.
Sadee means ‘our’ in Punjabi so Sadee Smile is ‘Our Smile’

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TOUCHSTONE
inspiring communities, transforming lives

Leeds Community Healthcare NHS
NHS Trust

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1. Executive summary

This is a summary of the evaluation report for Sadee (Our) Smile, a pilot course on living with diabetes specifically designed for South Asian communities in Leeds. The course is eight weeks long – four weeks on self-management followed by four cook and eat sessions where participants prepare healthy meals together. The course was delivered by non-clinical tutors of South Asian origin, who were trained by the Clinical Lead Diabetes Dietician who designed the course and supported by a Diabetes Nurse who delivered one of the sessions.

The pilot was a partnership between Leeds Community Health NHS Trust and Touchstone and consisted of 11 courses run in community venues in some of the poorest parts of Leeds. There were a total of 113 participants, the majority (88%) of whom were women with the biggest age group being those over 60. Over half of participants were of Pakistani origin and just over one third of Indian descent. Punjabi was the most widely spoken language.

The evaluation aimed to assess both the impact of the programme on the knowledge, skills and confidence of participants to be able to manage their condition, using the support services available to them; and to evaluate the course process in order to find out what worked well/not so well. Data collection was integrated into course delivery as far as possible with tutors using 'pre and post' quizzes to assess knowledge of diabetes and a 'readiness ruler' to check on views re the importance of self-management and levels of confidence to do it. Other quizzes and discussions were recorded on flipcharts and individual case stories collected. In addition the evaluators did two focus groups with participants and interviewed all three tutors and the two health professionals involved.

Key findings were:

- Knowledge and understanding of diabetes improved – by the end of the course virtually everyone understood that diabetes is for life, that it is not just a UK problem, and is more prevalent in the South Asian population. Plus they gained a basic understanding of how diabetes affected their bodies.
- Participants learnt not only that an appropriate and healthy diet is key to managing diabetes successfully, but what this meant in practical terms for them. Many reported making changes to their diet, particularly in relation to portion size and reducing sugar intake.
- Many participants increased their level of physical activity including walking, yoga, swimming, aerobics and gardening.
- Some people went back to their GP to ask for the health checks they were entitled to, and at least one changed his GP.
- People's confidence to self-manage their condition improved.
- Information about local support services was provided but little evidence was available as to whether participants accessed any other services.

Participants particularly liked that the course was run in their languages, in venues accessible to them and that it was culturally appropriate. Before attending the course most knew a bit about their condition and that they needed to change what they ate and be more active. But they lacked understanding of what that meant in terms of daily routines. They were very positive about how the tutors delivered the course and its very practical nature, including cooking together, plus they liked being able to share with others in the same position. All these factors meant that they were able to make real changes and developed a much more positive attitude to living with diabetes.

However participants did identify some barriers to self-management and living well with diabetes, in particular the following were mentioned:

- An expectation that unhealthy snacks (deep fried samosas, sweets, biscuits etc) are offered to visitors and accepted if offered to you when visiting.
- Women having less freedom than men to for example, go walking unaccompanied.
- Other health issues like arthritis making it hard to exercise and to lose weight.

- Being unable to converse well in English making it hard for example, to understand health professionals.

Participants were so positive about the course that they had nothing to say about improvement, other than that it should be longer, and/or there needed to be refreshers. Some people mentioned including family and carers and improving publicity so that more people could benefit.

The tutors and health professionals involved were also positive about the course and would welcome it being rolled out across Leeds. They thought that basically the course structure and content were right, but that care needed to be taken to ensure it remained up to date. The Lead Dietician suggested that something on mental health and stress management be included in future, but felt this could be incorporated within the eight weeks. The tutors thought that the nurse giving more information on medication would be appreciated. More resources were seen as being needed, especially more visual aids and models/replica foods and more time for tutors to prepare sessions.

In conclusion, this evaluation of the pilot course programme demonstrated that those of South Asian descent who have diabetes will attend groups which are held in accessible venues and where there are tutors who speak their language. Moreover many improved their understanding of diabetes, gained in confidence and knowledge and made changes which were beneficial to their health. Participants' skills in self-management improved and satisfaction levels with the course were high, indicating that this course has an important role to play in promoting effective diabetes management in South Asian communities.

Acknowledgements

We would like to thank the participants on the pilot Sadee Smile courses for sharing information about themselves with us and in particular for taking the time to talk to us in the focus groups. Your enthusiasm was inspiring.

We would also like to thank the tutors who painstakingly recorded a mass of information and shared it with us. We know this added to your workload and really appreciate the care you took to make sure that we had access to all the data collected.

2. Introduction

This is the final report of an evaluation of 11 courses which have run as part of a pilot programme in self-management of diabetes aimed at the South Asian community in Leeds. The evaluation was conducted by Health Together which is based at Leeds Beckett University and the programme is being delivered by Touchstone and funded by the Office of Public Health in Leeds City Council.

The courses

An eight week course was designed by the Clinical Lead Diabetes Dieticians, Leeds Community Healthcare NHS Trust, based on adult learning principles but tailored for the South Asian community. The first four weeks consist of group sessions covering various topics important to the self-management of diabetes. The second four weeks are cook and eat sessions where participants prepare healthy meals.

11 courses as part of a pilot, although groups five and six only ran for four weeks as the centre where they were based lost its funding. A breakdown of the courses run with dates and venues is provided in the table below.

Courses in 2015/16

Course 1	Touchstone Support Centre, LS8	13th July- 31st Aug	Men and women
Course 2	Islamic Centre, LS7	Sept- 27th Oct	Women only
Course 3	Touchstone Support Centre, LS8	21st Sept- 9th Nov	Men only
Course 4	Shantona Women's Centre, LS8	5th Oct- 23rd Nov	Women only
Course 5	Hamara Centre, LS11	20th Oct- 10th Nov	Association of Blind Asians
Course 6	Mary Sunley House, LS8	22nd Oct- 12th Nov	Association of Blind Asians
Course 7	Touchstone House	15th Feb – 11th April	Women only
Course 8	Touchstone House	15th Feb – 11th April	Men only
Course 9	Sikh Temple, Chapeltown Road	17th Feb – 20th April	Women only
Course 10	Bangladeshi Centre, Roundhay Rd	18th Feb – 21st April	Women only
Course 11	Touchstone CST	23rd Feb -12th May	Women only

A summary programme for the courses can be found in Appendix 1. Each course was delivered by two tutors trained by the Clinical Lead Diabetes Dieticians with a Diabetic Nurse facilitating week three. There were three tutors in all who spoke Urdu and Punjabi and various dialects between them (as well as English) and courses were delivered in first languages, with the tutors translating for the nurse. 113 people attended the 11 courses although not all were able to go every to every session.

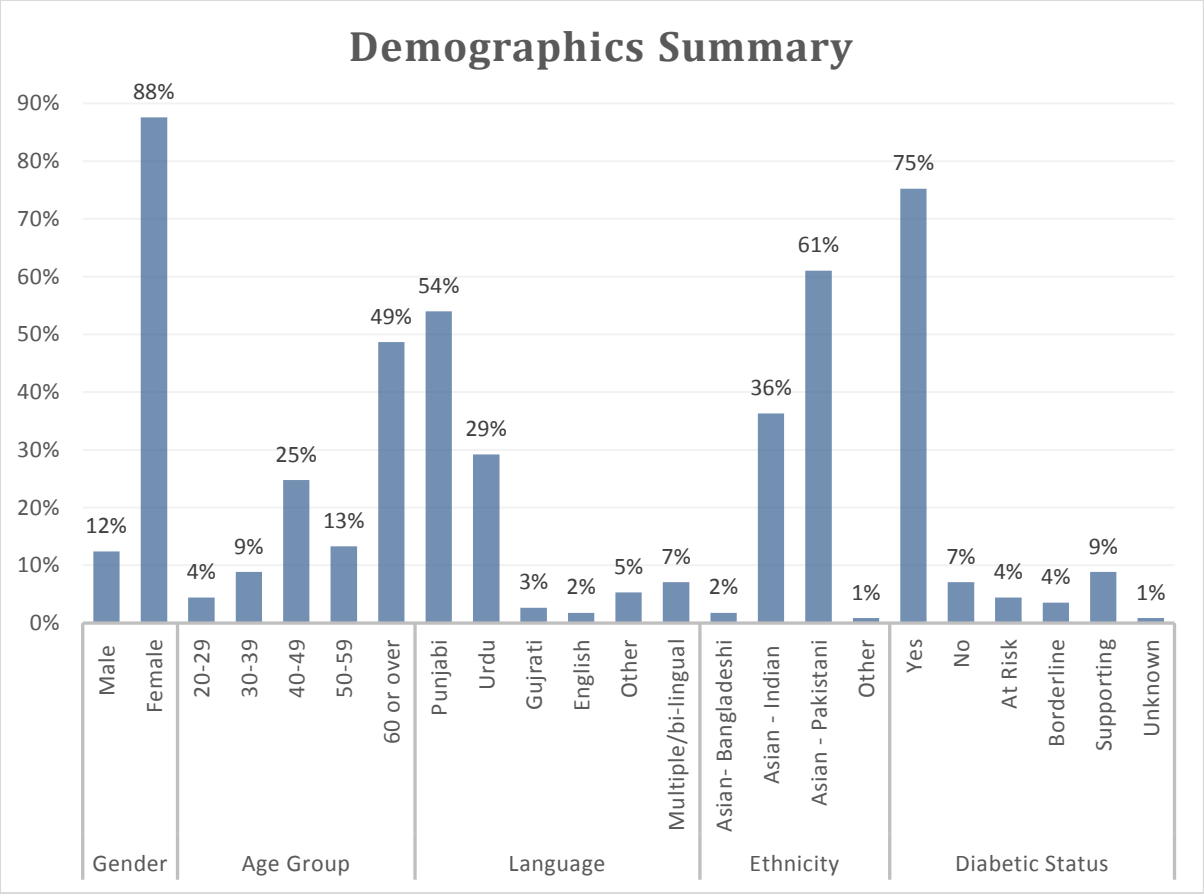
Participants were recruited by advertising the courses through voluntary and community organisations, leafleting outside mosques and word of mouth. There were only 26 people referred by primary health services across all 11 courses, not all of whom actually attended, although at the outset this was intended to be the principal mode of recruitment.

The course was designed to be general and fairly basic with the tutors delivering to a handbook designed by the Lead Dietician and with her support, she also quality assured the course. If people wanted more information than the tutors

were equipped to give, then they could refer them on as appropriate. There was recognition that people of South Asian origin with limited English were more likely to engage with a community based course especially if it was interactive allowing time for questions and discussion as well as information giving. The intention from the outset was to have:

''a lot of discussions where people talk about their views and their thoughts and the facilitator really guides them through the program rather than actually telling people what to do.'' (Dietician)

The bar chart below provides a breakdown of participants across all 11 courses. It shows that well over two thirds of participants were women; by far the biggest age group was those over 60; over half were of Pakistani origin, with those of Indian descent making up 36% of the total; Punjabi was the most widely spoken language and the majority (75%) of attendees were diabetic.



3. Evaluation aims and objectives

The overall aim of the evaluation was 'to assess both the **impact** of the programme on the knowledge, skills and confidence of participants to be able to manage their condition, using the support services available to them; and the **process** in order to find out what it was that worked well/not so well.'

The objectives were to assess:

- Participant knowledge re Type 2 Diabetes pre and post the programme
- Participant skills in self-management pre and post the programme
- Participant confidence in self-management pre and post the programme

- Participant awareness of local support services and how to access pre and post the programme
- Whether participant behaviour in relation to self-management has changed as a result of the programme
- Level of participant satisfaction with the content, structure and delivery of the programme
- Facilitator views on the content, structure and delivery of the programme and on impact. (this will be included in the final report)

4. Evaluation methods

As this was a small scale evaluation and in order to minimise any additional form filling by participants (or tutors on their behalf) the aim was to integrate the evaluation methods into course delivery as far as possible. The evaluation drew on the following:

- Four questions to test knowledge of diabetes pre course/at week one and at week eight
- Readiness ruler at weeks one, four and eight
- Discussion of self- management and lifestyle in weeks one and four
- Healthy eating quiz in week two and for later courses in week seven
- Discussion with nurse in week three
- Case stories of participants
- Focus groups with participants in November 2015 and May 2016
- Interviews with one tutor in January 2016 and with the other two tutors at end of programme (May 2016)
- Interview with Clinical Lead Diabetes Dieticians and Diabetes Nurse at end of programme

Participants to the two focus groups were recruited from the courses one, three and four and from courses nine, ten and 11 respectively. The first group needed to be English speaking as it was not possible to find anyone to interpret for the focus group leaders – the second focus group included non English speakers and was interpreted by two volunteers.

The quizzes, discussions and confidence ruler were all integrated into course delivery and used by the tutors as a way of engaging participants, gauging their level of knowledge and checking for any misunderstandings. Thus they were intended to be education as well as evaluation tools. Responses to the quizzes and the confidence ruler were recorded individually and shared anonymously with the evaluation team. Discussions were recorded on flipcharts, photographed after the session and shared with the evaluation team.

For a summary of data collected by week see Appendix 2.

5. Data Analysis

The responses to the quizzes and confidence ruler were summarised by course and where there was complete information (ie a participant had attended and completed for all weeks) this was included in the analysis. The two focus groups were transcribed and analysed to identify key themes. There was also an interview with a single male participant alongside the second focus group and this and the four interviews with tutors and health professionals were also transcribed and analysed. Similarly the flipcharts of discussions in the course sessions was analysed by grouping discussion of different aspects together and identifying any key themes.

Given the size of some of the groups and the amount the tutors had to do there are inevitably some gaps in the data collected but overall there was a rich variety of material collected and analysed - this is summarised in the next section.

6. Evaluation findings: participants

The findings of the pilot are summarised below in relation to the evaluation objectives.

5.1 Knowledge re type 2 diabetes

Participant knowledge pre and post the course was tested via a short quiz at week one and again at week eight. Data was also collected via the healthy eating quiz in week two and through discussions during the course and at the focus group.

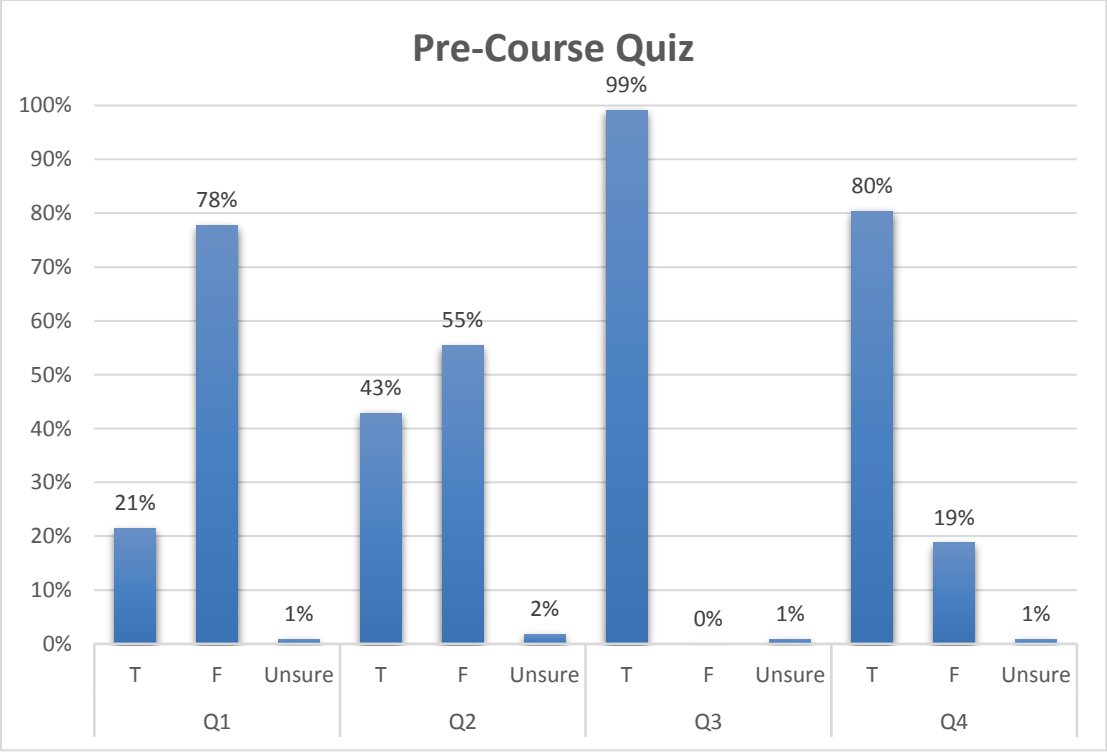
The questions asked in the pre quiz and the responses across all 11 courses are summarised in the bar chart below. The questions were:

Q1 Diabetes only affects people in the UK (False)

Q2 Diabetes is caused by eating too much sugar (False)

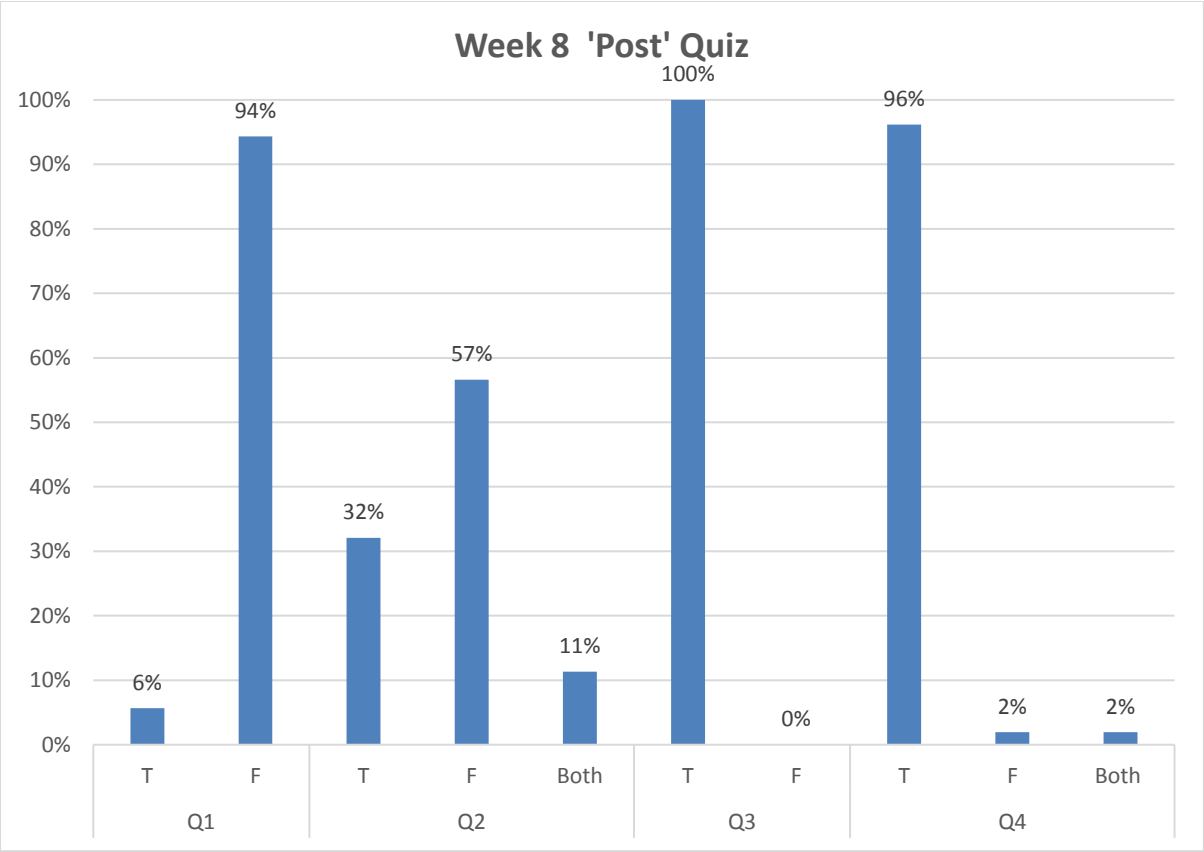
Q3 Eating the right things is one of the most important things you can do to control your diabetes (True)

Q4 Once you have diabetes you have it for life (True)



As can be seen from the bar chart, 78% of participants knew before the course that diabetes is a problem beyond the UK – but a sizeable minority (21%) thought it existed in the UK only. 55% rightly said that diabetes is not caused just by over consumption of sugar, but perhaps not surprisingly there was some confusion about this, given that eating too much sugar can lead to obesity which is a very important factor in the development of type 2 diabetes. Virtually everyone starting the course (who completed the quiz) already knew that eating the right things was one of the most important things they could do. 80% of people knew that diabetes is a long term condition.

The results or the 'post' quiz in week eight for nine of the courses are summarised in the table below - groups five and six finished at week 4 so did not complete the 'post' quiz and it should be noted that the numbers completing the 'post' quiz were only about half those who completed the 'pre' quiz.



As can been seen from the chart above, of those who completed both pre and post quizzes the proportion rightly saying that diabetes is not just a UK problem increased to from 78% to 94%; those saying that diabetes is caused by eating too much sugar went up by 2%; the proportion who knew eating well is one of the most important things they could do to manage their diabetes went up to 100% and those who believed diabetes is for life rose to 96%.

In summary, knowledge about diabetes was reasonably good at the start of the course but before completing the course a minority of participants thought that diabetes is just a UK problem and did not realise that diabetes is a lifelong condition. By the end of the course only a very few participants still thought diabetes is just a UK problem or that diabetes is not for life. There was some confusion about whether diabetes is caused by eating too much sugar which still persisted at the end of the course, but this is perhaps understandable given that it can be a major factor. Perhaps most importantly everyone who completed the post quiz knew that what they ate was critical to managing their diabetes.

At the start of the courses (this was tested in week two as part of the healthy eating quiz) 76% of participants knew that diabetes is more common in the South Asian community.

In the focus groups most participants said that they 'didn't know much about' diabetes when they started the course. For example a participant in the second focus groups said:

''we don't know much, all we know is take the medicine, tablets or insulin.''

From the discussion it would appear that when they said they 'didn't know much' they were often referring to not knowing about how to manage their diabetes and this was the overall impression of the tutors across the courses – even where people had some basic knowledge they did not understand what was going on in their bodies, or know much about what they needed to do on a day to day basis to live well with their diabetes. In the first course some

participants were recorded giving their views on what they had learnt. This is what one participant said (translated by the tutor):

'We have learnt a lot about diabetes. About how we can control our sugar cravings and how the pancreas produces less insulin in diabetes. If we will eat less sugary foods, we can be healthier. Diabetes is very common in our community. We should always keep an eye on our sugar levels, eat healthy, eat more salads and eat a piece of fruit if we are having a sugar craving. (Participant, translated by the tutor, *course 1)*

5.2 Skills in self-management pre and post the programme and whether changes were made

How to manage their diabetes was discussed on the course, particularly in weeks one and four. It was also discussed in the focus groups. Themes from the course discussions were analysed for each week across all courses and are integrated into the analysis of the focus group discussions below.

Managing their diabetes was a major theme and covered:

- Healthy eating – particularly cutting down sugar, increasing fruit and vegetable consumption and portion control
- Becoming more physically active – mainly through doing more walking, but yoga was also mentioned a number of times
- Taking medication correctly was mentioned by two focus group participants and this plus going for regular checks at their GP practice came up a lot in discussion on the courses.
- Drinking plenty of water was also talked about in course discussions
- Reducing stress was mentioned in some course discussions but did not come up in the focus group

Of these themes, making changes in what they ate was discussed the most in the courses. As well as reducing sugar intake, increasing fruit and vegetable intake and portion control, cutting back on fat and eating less fried food was mentioned frequently. Changing the type of oil used came up a few times as did eating more nuts and fish. Participants were encouraged to set goals and these included '*watching my portion size', and a 'balanced plate'.* Finding changing eating habits hard came up in most groups and is discussed below.

All 18 focus group participants talked about the changes they had made while and since attending the course. Dietary changes were mentioned most often:

'instead of four biscuits we used to have, we take only one or two' (P3)

'I stopped sugar in my tea...and now I'm trying to go on less chapattis' (P6)

'(I've) cut down on portions' (P7)

'I eat more healthy foods, a lot of vegetables, fruits, eat less sugar, sugary things' (P 4)

'Before this course I was just eating anything, and there was no control and no nothing....this course has really, really, helped me.'' (male participant, individual interview)

There was some discussion about the custom of taking sweet things as presents, especially on festive occasions, but also of an effort to cut down on this:

'We used to buy a lot of sweets....but this Diwali we didn't, only a few' (P6)

'It's just when you go to somebody's house visiting and they put samosas out...''(FG 2)

There was also some discussion of family members and friends making changes:

'*my son and his wife have changed their diets completely...they are not introducing any sugar into (their baby daughter's) diet. So I think it's partly learning from what me and my parents have gone through that has made them very careful' (P1)*

One participant talked about reducing their alcohol intake:

'alcohol has a lot of sugar, right....well I've stopped it, nearly stopped, almost' (P4)

Taking more exercise was discussed on all the courses and some focus group participants talked about increasing their physical activity:

'I walk in Golden Acres park, walk around – I think about 2 miles, not more, two or three times a week' (P5)

'I used to get the bus from my house to Headingley – now I walk' (P3)

The need to take their medication and to do so at the right time, plus concerns about the level of support they were receiving through their GP practice was came up quite a bit in course discussion. For example on course five, participants talked about needing more support from their GP, having to wait too long for appointments (one month was mentioned by one participant), not having had their feet checked for two years (one person):

'only get appointment after one month – useless for diabetes' (P4, course 5)

'I've not had my feet checked for over two years' (P13, course 5)

Not receiving support or care in their own language was mentioned as a barrier for some and on the course itself, one participant who spoke pretty good English, mentioned that he found it '*a little difficult*' following the nurse, although what she said was translated by the tutors.

In the boxes below two of the tutors tell two course participants' stories.

Case Study 1

This lady was in her forties and had had type 2 diabetes for 10 years; she takes oral hypoglycemics and long lasting insulin. She was of Pakistani origin and spoke Punjabi. She found out about the course from the diabetic nurse at her GP surgery. She had no reading or writing skills so was unable to read hand outs or fill in the food diary or evaluation forms on her own. She wanted to understand her condition better, to eat better and to lose weight. She needed to gain in confidence and motivation to make changes. We took time to explain things to her one to one and although she had attended two courses about diabetes before, this was the first time that she felt she understood what actually happens in the body when you have diabetes. She has started to eat a healthier diet including more salad, fruit and vegetables and using recipes we tried out on the course. She has bought ingredients she had never heard of or tried before such as quinoa. She has lost weight and is taking more exercise.

Case study 2

One participant on course three, she and most of her family have diabetes and she was cooking everything for her family at home. She wasn't educated, she couldn't speak any English, and she just seemed like she had, the first week she just had very little capacity to make changes in her own life. She was very overweight, and quite low in terms of mood towards her health I suppose, but by the cooking sessions, I was really surprised to hear what she was saying, she was saying she was cooking these meals for her family, for her son and they were eating it and liking it and she was taking the recipes home for somebody else to read out to her too.

5.3 Participant confidence in self-management pre and post programme

Course participants were asked to score 'how important it is for you to make a change' and 'how confident you feel that you can make changes in your lifestyle' with a score of 10 being the highest and 0 the lowest. They did this in weeks one, four and eight. As attendance was a bit erratic on some courses, courses five and six finished after week four, plus week eight was the last cook and eat and it proved harder to get people to fill forms in at a practical session, there is only complete data for 47 people, but there is data for weeks one and four for 101 people.

Analysis of the 101 who completed the 'readiness' rulers for both weeks one and four, indicates that understanding of the importance of making changes was reasonably high from the outset - all but four participants scored themselves as 5 + and there were 46 who scored this as a 10. At week four 30 people had increased their scoring of this statement but 15 had decreased it, albeit usually only by one point (the rest scored it the same).

In relation to confidence to make changes, the scores people gave themselves for this varied a lot, but in contrast to the scoring on the importance of making a change, at week one, 34 scored themselves at 5 or lower and overall all bar 13 participants rated their confidence to make a change lower than the importance of doing so. By week four 48 participants out of 101 rated their confidence as higher, with 13 rating it lower than at week one (the rest scored it the same).

For the 47 who also completed a confidence ruler at week eight, 17 rated the importance of making a change higher than they had at week four and nine rated it lower. With regards to confidence this had gone up between weeks four and eight for 22 participants and decreased for ten (the rest scored it the same).

This analysis of these results indicates that for many participants their understanding that making a change was importance and their confidence to do so improved, but that this was not the case for everyone. However these results can at best be considered indicative only and should be treated with caution as there are many factors which can influence scoring. For example it is not uncommon for confidence to decline in courses such as this, as participants who felt reasonably confident to start with realise that they do not know as much as they thought they did. Also there are many factors which can affect how confident someone feels on a particular day, and it's quite possible that confidence for some dipped at the end of the course and they realised that they were now 'on their own'. It should also be noted that participants did not have their previous scores to hand so were not necessarily making a comparison with, for example, how they felt at the start of course when scoring their confidence level at weeks four and eight.

In the focus groups there was a general feeling amongst participants that their confidence had grown: *'(I feel) pretty confident' (P2) 'very confident' (P1)* but also a recognition that it could be difficult to always manage their diabetes well:

'To be honest we are controlled, but not a lot. We try to walk, but sometimes you know, like now Christmas coming, people get carried away..' (P4)

These responses were made to a question about how confident they felt about managing their general health following the course:

'we improve quite a lot but not 100%' (P5) '75%...still some work to be done' (P7)

This recognition that they had not got management of their diabetes totally sorted can be seen as realistic and more positive than any false confidence that they were 'sorted'.

5.4 Awareness of local support services and how to access

There was some reference in the notes of course discussion about leaflets being given out re local activities but this was mainly assessed through the focus groups where the response to this question was limited. Participants mentioned having been given leaflets about different things, possibly including services; about a course at the University; the possibility of a walking group via Touchstone was mentioned and the need to go for regular checks at their GP surgery:

'Go to your doctor every six months....for a blood check. Because is changes, doesn't it, because he prescribes.' (P7)

This same participant complained that it took her GP one year to test her for diabetes, although she was feeling unwell throughout that year.

5.5 Participant satisfaction with the content, structure and delivery of the programme

Most of the data for this section was gathered in the focus groups, but some participants did feedback during the courses. This participant from the first course was asked to give his feedback on film. His words summarise most of what the focus groups participants said in relation to the changes they made, the benefits in terms of their health and the delivery of the programme:

'I've received a lot of benefit from this course. My sugar levels used to be very high, around 18 to 19mmol/L. But now since I've attended this course, my sugar levels are more under control, around 7 to 8mmol/L. I've learnt what to eat and what not to eat from this course. I consider myself healthy now and know how to control my weight. I advise you all to join this course and tell all your friends and family about it. It's an 8 week course. The teachers have been great on this course and are very helpful. This course will definitely make a difference to you.' (Course 1 film clip translated)

In the focus groups, participants talked about how much they had learnt. Most said they did not know much about diabetes or how to manage or prevent it before they went on the course:

'I didn't know much about it – I learnt a lot.' (FG P1)

This participant knew a bit but welcomed the chance to check their knowledge:

'I knew a little bit, because I've got diabetes in the family – I think this is a good course to learn a bit more reinforcement, some of the things I wasn't quite sure about.' (FG P4)

This comment from a participant on course five was typical of many:

'We never received this information before, (we've) not heard about HB41C' (C5 P3)

In terms of course delivery that courses were run in their first language was welcomed by focus group participants:

'We enjoyed it, it's very good and in our language as well, so we understand more.' (FG P3)

Delivery in community venues convenient to them was also valued, as was delivery by a trusted local organisation:

'We expect good things from Touchstone' (FG P2)

The practical nature of the course was appreciated – for example the sharing of recipes demonstrating how to cook in a more healthy ways and the chance to actually try them out; and the use of a food diary:

'The level of involvement in terms of actually doing the cooking as well, that was a bit more than I expected, which was good.' (FG P1)

'They gave us leaflets and you fill up what you eat in one day, so we used to fill it up, so we were learning..' (FG P4)

'A bit they did that was really good was showing you on a daily basis, as you go through your routine, how much sugar and fat you're building up. That was an eye-opener.' (FG P1)

'To measure a portion right, you take one of your palm or hand and try to put it (the chapatti dough) there. The same with rice you know, I used to take a full plate of rice, now I just take half'' (male participant interviewed individually)

The tutors were praised for their dedication and their approach. This participant expresses how they helped allay her anxiety about diabetes:

'*Everything was very nice and these teachers (names) they were very good. (having been told we were borderline) we are very anxious to know more about it.' (FG P6)*

Participants enjoyed being part of a group:

'*we came out as well, it was a change.... I enjoyed everyone's company.' (FG P6)*

'it's the atmosphere' (FG P5)

'we learn from each other as well.'(FG P3)

'we can gossip a bit,' (FG P2)

When asked about what they thought of the course overall the unanimous response from focus group participants was that it had been 'very good'. 'wonderful', 'excellent', 'informative'.

5.6 Barriers to making changes

Participants in both the focus groups and in the course discussions about making lifestyle changes identified challenges or barriers to making and maintaining change. Cultural expectations to eat (often sweet or fatty snacks) when visiting others and to offer food when people came to them presented challenges, which some participants were responding positively to:

Before if you used to go to somebody's house, they'd have all sweet things, cake, biscuit and all that, but nowadays we're careful.' (FG P5)

One participant in focus group two mentioned how jalebi sweets were put on her plate when she visited the temple and how she found it very hard to say she did not want one!

There was some discussion about how their grandchildren expected to be given sweet things and how hard it was to change this:

My grandchildren, they'll have what they want. If they want ice-cream, they want ice-cream – that's it.' (FG P2)

In discussion on the courses several participants mentioned barriers to exercise – both their physical health and cultural expectations about appropriate behaviour for women:

'I have too many aches and pains, so it is hard for me to exercise.' (C5 P7)

One participant in focus group two got upset when she talked about how much her arthritis affected her ability to exercise, despite wanting to follow advice that this would help her diabetes.

There was a discussion in course four about how in general change was more challenging for women because:

'For Muslim ladies, it's harder to be exercising alone. (C4 P7)

'Men have more freedom – women have responsibilities.' (C4 P5)

Not liking healthier foods was a barrier for some – brown rice in particular was unpopular. Participants were realistic and realised that:

'(there is) still some work to be done, because you've got our Asian habits..we cook different ways.' (FG P7)

5.7 Ways in which the course could be improved

Participants in the focus groups were overwhelmingly positive and so, not surprisingly, the main way in which they felt the course could be improved was if it went on for longer:

'We could do with maybe 10 or 12 (weeks). Because we were just getting into it. We got to the point where we all gelled as a group, then it finished.' (FG P1)

More use of traditional Asian recipes and how to make them healthier was suggested:

'how could we revert to an Asian cooking that was a lot healthier, that would have been useful.' (FG P2)

There was also a feeling that the courses should be better publicised (although the tutor who distributed leaflets at the mosque was considered very brave!) as the focus groups thought there would be a lot of people wanting to go. In focus group two there was a discussion led by a woman caring for both diabetic parents about how important it was for carers and family members to be able to attend this sort of course. Participants suggested advertising by visiting temples and mosques, sending letters to people, giving out information when people went for check-ups etc.

The group were unanimous in saying that they would recommend the course - these quotes sum up what they felt:

'A big word of thanks to both the girls that ran it, it was really, really good.' (FG P1)

'It's the way she (tutor) has done it you know – with all that love and enthusiasm within herself and (other tutor) also.' (male participant interviewed individually)

7. Evaluation Findings: the views of the tutors and health professionals involved

The dietician who designed the course, the nurse who delivered the majority of the nurse led sessions in week three and the three tutors who delivered the course, were all interviewed. Their views of the course are summarised here.

The Clinical Dietician with lead responsibility for diabetes who designed the course was very supportive of delivery by non clinical peers. She felt that the course had gone really well, in large part because of the excellent delivery by the tutors:

''I think they've been very positive, they've been very open to come to ask for help and double checking that what they doing is right so I feel quite comfortable with that that they weren't going off on their own tangents.....they just get on in there and get on with what they need to do and everybody seems to know what they're doing and the group that I quality assured certainly ran pretty well.''

She also commented that because the courses were run in first languages and in community venues the engagement was better than if they had been run by health professionals:

'(Touchstone) is more accessible to the type of cliental that the groups were aimed at (and) they are more likely to stay, more likely to engage, if it's in their own language.'

She was impressed by the initiative the tutors demonstrated in recruitment when referrals did not come in as planned, and in the amount of engagement they got on the courses:

''I didn't think they'd get men in the kitchen but they did… These ladies actually, they can cook, you don't need to teach them to cook, they can cook, and they like the social interactions so I think it's worked really well.''

One of the male participants commented on the cook and eat sessions:

''I'm not a very good cook but I did salads and different things and they were lovely. I was taking it home and showing my wife and she was surprised...how much we had been eating wrong stuff.''

The nurse who was interviewed commented on how well providing education on diabetes in a group setting worked because ''*they sort of bounced off each other and shared things so I think that was good.''*

The three tutors who were involved also felt that the courses had gone very well and saw the fact that attendance was generally good for the full eight weeks and there has been demand for sessions as clear evidence of their popularity. There is a demand from carers and family members as well as from people with diabetes, which given that those trying to self manage their diabetes need the support of those close to them, they saw as a positive thing. Like the clinicians they emphasised the importance of courses delivered in first languages although this could be challenging for them as there are so many different dialects.

Both the health professionals and tutors involved felt that the smaller groups had worked better than the couple of larger groups. As the tutors said:

''If they are bigger groups then I find you lose some of the interaction. Whereas the smaller groups you can engage and it's quite easy you know, to get engaged.''

''towards the end I've seen with the smaller groups they star exchanging numbers as well...'Oh we'll keep in touch, we'll do this together, we'll do that together'. So I think developing those relationships amongst themselves as well is important.''

Cooking sessions were hard to deliver with bigger groups and inevitably only a few could be in the kitchen at once, with others dipping in and out.

In their engagement with the courses, the clinicians had seen participants gain in confidence, improve their knowledge and understanding, and feel empowered to make changes and ask for the health care they were entitled to:

''Many of them didn't understand the impact of carbohydrates on their blood/glucose levels, so I think that was quite an eye-opener for some of them. One gentleman realised that he hadn't been having as much care from his practice that he should have been having and he actually changed his GP because it highlighted in week three the care that he should expect, so I think that's empowered people to be able to say actually, yeah I need my urine tested on a regular basis, I need my eyes tested on a regular basis and enable them to question if it isn't done, so I think that's a very valuable part of what the program has done.'' (Dietician)

''there were quite a few misconceptions around that (medication).....some were quite shocked because they weren't receiving (the health care they were entitled to) and intended to go back and ask why....some of them were receiving everything they should be receiving and probably didn't understand why, so they were getting that by the time they'd finished.'' (Nurse)

The tutors also observed changes, and like the clinicians commented on misinformation about carbohydrates:

''so they are making lifestyle changes, and it's small changes so that when they've advised us that they are eating smaller portions or they're conscious of what they are eating, they are actually conscious of how many spoonfuls of rice they are having and being able to differentiate the food groups. And it's good to hear they've started walking, it's good to hear they've actually you know making more time out to do some form of exercise, if they can, and build it up.''

''A lot of the things are really like eye-openers for people especially when it comes to the carbs. A lot of people have the misconception that they shouldn't have it at all, they need to avoid the carbs, and because of that they are suffering low sugar levels, and low energy levels.....

Information about portions was very helpful as *''with the South Asian group, we never think about our plate size, or what should be on our plate.''*

The tutors also observed that participants were often unaware of the health care they should be receiving and *''did enjoy the nurse's session in regard of you know the information delivered.....and about when you go to your GP what to expect. Some of the women didn't have that expectation, so it was new information that they learnt about what they should expect from their GPs.''*

Tutors commented that:

' (participants) did come with some knowledge about diabetes but the main important things is about our understanding what it actually is. How it works in your body, they didn't come with that knowledge.'

So giving fairly detailed information about what was going on with the body helped people to understand that they could not 'make the pancreas more healthy' and reverse their diabetes, but also that they should not blame themselves. One of the tutors also reflected that diabetes was so common in South Asian communities that sometimes it was seen as the norm and its seriousness put to one side, so the course was challenging that viewpoint:

(when the nurse explains) it brings it home to them because it's quite, diabetes amongst our community is so common now that it's just like yeah you take it for granted that somebody has it rather than doesn't. So I think the seriousness of the condition as well it's quite..... the room would always go very silent at that point…''

A participant in the second focus group also commented on this:

'*It's quite hard to hear when somebody says diabetes isn't for one day or two days it's for life. And when you think about it, it's not a little matter it affects the whole of your life and the people that live around you.'*

The main changes talked about related to diet, but the tutors also talked about how some participants had become more active, mentioning walking, badminton, yoga, aerobics, gardening, swimming and water aerobics as all being mentioned. Two of the groups had got together towards the end of the course and formed a walking group meeting once a month or so to walk together.

Overall the tutors observed that as their understanding and knowledge improved, and they started to make small changes, participants' confidence grew:

''since they've gained the knowledge they have.....you can see there's more confidence in them talking about the changes that they've made, and you know how happy they feel about it, and how it's affected their health as well. So then when they have the conversations, "oh well I was able to do this today" etc. So, that's what I found. If you are not confident you are not going to really be discussing that or really opening up in the group. so we had a few in the group that were, you know the people that don't really talk but they obviously listen, but at the end of the eighth session they were all starting to talk and openly discuss confidently about their health, and about the changes they've made.''

Having initially thought eight weeks would be too long, the Lead Dietician was pleasantly surprised to find that it worked really well:

''(if you condense it down) you are going to lose some stuff that you've not covered and bear in mind if you're working in a different language, particularly week three (when the nurse delivers) it takes twice as long to get the information over working through an interpreter so you have to allow more time for that. So personally being sceptical at the beginning I wouldn't now change it because as I say it's worked.''

The tutors also thought the length of the course was right.

In terms of the future both clinicians thought the course should be rolled out across Leeds. They thought that basically the course structure and content were right, but that care needed to be taken to ensure it remained up to date (eg incorporating changes to the eat well plate). The Lead Dietician thought it important to include something on mental health and stress management in future, but felt that could be incorporated within the eight weeks. The tutors thought that the nurse giving more information on medication would be appreciated. More resources were seen as being needed, especially more visual aids and models/replica foods.

Supporting participants to sustain changes made was raised with the suggestion that occasional reunions are organised, additional course sessions if advice changes and support given to ongoing peer led activities:

''groups of people getting together and forming walking groups or social/cooking groups or whatever, to keep the momentum going.''

Recruitment remains an ongoing issue and to get easier to get GP referrals needs them to be confident in and enthusiastic about the programme:

''GPs and practice nurses have to also be engaged in the value of the groups to pass that attitude onto the patients.''

Tutors pointed out how a GP or nurse just telling someone about a course is unlikely to be enough:

''With our community it's really important to go out and gain the trust of that person, where they're going. Is it going to be an all-women's, are there going to be men there, where is it going to be held, are there going to men in the building, these are questions for some of the ladies attending these groups… is it secure, is it safe, can I bring my kids, there's a lot of things that feed into whether that persons going to come or not, so for us it's about minimising the barriers for them to access the group.''

The tutors commented on the amount of time it took to set up each course and to prepare for each session and felt that the time allocated was not enough:

''a lot of work that goes into each session. A lot of planning, a lot of preparation, setting up, travelling and packing up again. Some of the sessions go over time, just it is really time consuming.''

Evaluation also takes time and added to the pressure on tutors who nevertheless showed a high level of commitment to ensuring that evaluation information was collected. The Lead Dietician also commented on the amount of time the tutors put into delivering the course, including collecting data for the evaluation.

Tutors felt strongly that the programme should continue and had a lot of people and groups interested. The value or the course to the health professionals is summarised by the Lead Dietician:

''I would like to see it rolled out, you know we've put a huge amount of work into it, it's worked, I think it's been successful, although I haven't seen the full evaluation of it, and it would be such a shame if a stop was put on it now.''

8. Conclusion

These results from the 11 courses of the pilot programme demonstrate that those of South Asian descent will attend groups which are held in accessible venues and where there are tutors who speak their language. Moreover many improve their understanding of diabetes, gain in confidence and knowledge and make changes which are beneficial to their health. Participants' skills in self-management improved and satisfaction levels with the course were high, indicating that this course has an important role to play in promoting effective diabetes management in South Asian communities.

Appendix One: SADEE SMILE Course Summary

(South Asian Diabetes Education Empowerment and Self-Management in Leeds.)

SADEE SMILE is an 8 week programme 2 – 2 ½ hrs per session designed specifically for the South Asian Community to increase knowledge and self-management skills in people who have T2 Diabetes.

The programme was commissioned by Leeds city council, it is led by Touchstone (a non profit organisation which supports vulnerable communities). Touchstone has worked in partnership with Leeds Community Healthcare Diabetes service and Leeds University to develop and evaluate the programme.

The programme is delivered within communities in Urdu, Punjabi and Bengali. It consists of 4 "classroom" sessions followed by 4 cook and eat sessions. The programme was designed around adult learning principles, the first 4 sessions are highly interactive and contain a lot of visual props with minimal written material (although this is available if requested). A summary of each week is given below:

Week 1 – explores what is diabetes and the importance of body weight in managing diabetes.

Week 2 – focuses on healthy eating and the importance of carbohydrates in blood glucose control.

Week 3 – led by a diabetes specialist nurse with an interpreter, this week focuses on the importance of blood glucose, blood pressure, blood fat control. Importance of annual review, foot care and regular retinal screening.

Week 4 – revisits food with the food diary exercise where participants assess their own diets. Looks at the benefits of physical activity and making sense of the myths that surround Diabetes. Time is set aside to plan for healthy cooking sessions.

Weeks 5-9 – cook and eat sessions where participants put the learning about healthy eating into practice in the kitchen.

The programme has been evaluated throughout with the support of the University and the staff delivering the programme trained and quality assured by Leeds Community Healthcare Diabetes Service. The programme was written by staff in the Diabetes Service , with input from those delivering the programme.

Appendix Two: Data Collection Methods

Week	Methods	Objectives measured	How recorded
One	Quiz Group discussion about self-management and lifestyle. Readiness ruler	Participant knowledge re Type 2 Diabetes Participant skills, confidence and behaviour self-management. Knowledge re how lifestyle impacts on diabetes Importance of making changes and confidence to do so	On template Key discussion points on flipchart Readiness ruler done individually and sheets collected in.
Two	Quiz re healthy eating use apple/pears to record yes/no answers Food diary started	Participant knowledge and behaviour re healthy eating and impact on diabetes.	Responses to quiz recorded on a flipchart
Three	Quiz re diabetes and medication (if nurse is OK to do this) Group Discussion	Participant skills, confidence and behaviour re self-management of diabetes	Responses to quiz and key discussion point recorded on a flipchart
Four	Readiness ruler Group discussion	Participant confidence re self-management Knowledge re lifestyle & impact on diabetes	Readiness ruler done individually and sheets collected in. Key discussion points on flipchart
Seven	Quiz re healthy eating repeated	Participant knowledge and behaviour re healthy eating and impact on diabetes.	Responses to quiz recorded on a flipchart
Eight	Quiz Readiness ruler	Participant knowledge re Type 2 Diabetes Participant confidence re self-management	On template Readiness ruler done individually and sheets collected in.
Mid November 2015 & May 2016	Focus groups	Participant awareness of local support services and how to access pre and post the programme Participant satisfaction with the content, structure and delivery of the programme Participant knowledge, skills, confidence and behaviour re self-management	Digitally recorded and transcribed
April/May	One to one interviews	Tutors, Nurse and Clinical Lead - views on structure of programme and impact + include all other objectives.	Digitally recorded and transcribed
On-going	Case studies	Combination	On template by tutors