Structured diabetes group education for UK south Asian communities

Ripanjit Gill, Rupindar Sahota, Jacob Leveridge, Sarvesh Saini, Dylan Tomlinson

Article points

1. The main aim of this X-PERT-based programme was to provide accessible and effective structured group education in diabetes for UK south Asian communities.
2. The primary outcomes were HbA_{1c} level, blood pressure, BMI, total blood cholesterol, and waist circumference.
3. In light of the barriers to education for south Asian groups identified to-date, it seems reasonable to infer that participants' results improved following this programme because it was adapted to cultural needs with respect to language, literacy and accessibility.

Key words

- Education
- Hounslow
- South Asian
- X-PERT

Author details can be found at the end of the article.

Structured education is a key ingredient in supporting people with diabetes to gain greater knowledge, confidence and efficacy in self-care. This study aimed to adapt structured education to address cultural differences, with a view to improving diabetes education for UK south Asian people and to assess any benefits. South Asian people with type 2 diabetes were recruited from the Hounslow area of London to take part in a 5-week X-PERT-based structured education programme, delivered in either Punjabi or Hindi. Primary outcomes were an improvement in HbA_{1c} level, blood pressure, BMI, total blood cholesterol and waist circumference. Secondary outcomes were diabetes knowledge and empowerment (measured by questionnaire). There was a trend towards improvement in all primary outcomes at study end.

Structured education programmes became a requirement for the NHS to provide as part of the National Service Framework for diabetes (Department of Health [DH], 2001; 2004; DH and Diabetes UK, 2005). Although NICE (2003) noted a lack of high-quality trial data to support structured education, the evidence base was considered sufficient to recommend group-based adult education aimed at improving control of risk factors, self-management and quality-of-life.

However, there is a lack of evidence to show the effectiveness of such education for UK south Asian people, among whom, levels of diabetes are three- to five-times higher than in UK white people, and for whom support needs are thus more extensive than would otherwise be anticipated for a population of this size (Mather and Keen, 1985; Burden, 2001; Oldroyd et al, 2005).

Specifically, NICE (2003) recommend that within adult education groups, participants should be able both to share knowledge, and to receive support in further learning. NICE also advises that programmes should be provided by a suitably trained multidisciplinary team, comprising at the least, a diabetes specialist nurse and a dietitian.

The X-PERT education programme (Deakin et al, 2006), from which the intervention described in this article was developed, is one of several designed in the NHS to fulfil the above principles.

Issues for UK south Asian communities

To accommodate participants for whom English may be a second or "other" language, the preferred practice in structured education appears to be to provide translators, or clinicians fluent in the relevant languages (Deakin et al, 2006; Allard, 2007) to increase understanding of programmes delivered in English. How far this overcomes barriers to participation, and attainment of health or other benefits, is unclear. Although this approach was used for south Asian participants of Deakin et al's (2006) randomised controlled trial of the X-PERT programme, the trial was not designed to test effectiveness for south Asian people as a group, in terms of numbers needed for data analysis.

While outcomes for participants of the study by Deakin et al (2006) as a whole suggest that the programme has been very effective at improving knowledge, motivating individuals to take control of their condition and achieve glycaemic control, it is unclear to what extent the specific cultural and educational needs of south Asian people have been met, or whether it has been effective in these particular groups. There was also a high degree of illiteracy, and a low return rate for assessment questionnaires among south Asian participants (Deakin et al, 2006; undated).

Choudhury et al (2009) found that a much shortened 4-hour X-PERT programme (the full programme is normally 12 hours), run in one session by peer educators in Sylheti, for a UK Bangladeshi community, was associated with moderate levels of improvement in diet, exercise and foot care 1 month after delivery. However, groups were not large enough to test for statistical significance.

Diabetes and the south Asian population in Hounslow

Hounslow is an outer London borough situated between Kew and Heathrow airport. It has a substantial minority ethnic population, largely made up of south Asian communities. At the 2001 census, the minority ethnic population was recorded as 35% (Learning and Skills Council, undated). About half (17%) defined themselves as "Indian" and 4% as "Pakistani". In central and north Hounslow electoral wards, people who define themselves as "Indian" form between 31% and 42% of the total population (Simpson, 2005). The predominant languages spoken, aside from English, are Punjabi, Hindi and Urdu.

Earlier initiatives on diabetes education found that a significant proportion of UK south Asian participants do not read and write in English, or in their first languages. Wilson et al (1993) reported that 48% of south Asian participants in diabetes education were unable to read in any language, and 80% unable to read in English. Simmons et al (1991) reported that 25% of south Asian participants could not read in any language. Results from a diabetes self-management trial showed that only 35% of south Asian participants could communicate in English fluently (Vyas et al, 2003).

Aap ki sehat aap ke haath (your health is in your hands): Aims and development of the Hounslow programme

The main aim of the programme was to provide accessible and effective structured group education in diabetes for south Asian communities, particularly for older people, who were noted locally as less inclined to attend. It was thought that if structured education was provided in south Asian languages, in community settings rather than at hospitals or health centres, and using a content and style adapted to cultural

Table 1. The Hounslow south Asian X-PERT curriculum.

Week 1	● Understanding diabetes. ● Significance of glucose and insulin production (using X-PERT visual aids). ● Insulin resistance – the impact of lifestyle. ● Blood glucose monitoring – targets, methods of monitoring (for example, home blood glucose testing, the significance of HbA_{1c} is explained). ● Introduction to diabetes annual review. ● Watch DVD "Understanding and managing diabetes".
Week 2	● Recap on week 1. ● Diet and weight management, obesity health risks and role in diabetes. ● Energy balance and weight control. ● BMI, waist measurements and their significance. ● Benefits of exercise and healthy eating using the Balance of Good Health (Healthy Eating Plate model) X-PERT resources. ● Estimating calories. ● Watch DVD "Healthy Asian cooking and shopping". ● Group exercise: Review your own meal plan and estimate calories.
Week 3	● Recap on week 2. ● Emphasis on carbohydrate amounts using X-PERT carbohydrate/glycaemic index models, glycaemic index concept. ● Quiz on carbohydrate and glycaemic index. ● Estimate of carbohydrate for each person's meal plan. ● Saturated fats and unsaturated fats, including the role of omega 3 fatty acids. ● Guidance on foods. ● Cooking tips for Asian cooking using less oil. Alcohol guidelines.
Week 4	● Recap on week 3. ● Short-term complications: symptoms of hypoglycaemia and hyperglycaemia, causes and treatments. ● Impact of illness on blood glucose levels. ● Long-term complications: cardiovascular disease, nephropathy, retinopathy. ● Foot care: management and prevention of foot complications. ● Interaction of blood glucose, blood cholesterol, blood pressure, and lifestyle using X-PERT visual aids.
Week 5	● Recap on week 4. ● Diabetes medication: blood glucose-lowering therapies and blood pressure and lipid-lowering tablets. ● Adherence issues. ● Alternative therapies (for example, karela, cinammon, green tea, fenugreek): pros and cons and evidence. ● Diabetes review: myths and misconceptions about diabetes. ● Goal setting: each participant starts completing a personal lifestyle change form and sets goals for changing lifestyle. *Question-and-answer session each week.*

needs, then this would lead to an increased level of interest and participation.

Owing to lower levels of literacy in both first and other languages, the X-PERT programme, with its use of visual materials as tools to promote adult learning, was felt to be the most appropriate.

Following consultation with the X-PERT programme team, possible structure and content was discussed with local south Asian community groups, and a modified, but full-length version of the programme was devised, in which additional visual materials were included, and consideration of traditional medicines and south Asian diet highlighted (*Table 1*). A dietetics assistant was recruited and trained to run education sessions directly in either Punjabi or Hindi (without using a translator or interpreter), under the supervision of a bilingual diabetes specialist dietitian, who also attended some sessions. As Baradaran et al (2006) note, Punjabi is easily understood

by Urdu speakers, and it was judged unnecessary to add separate programmes in Urdu. The sessions were held in community settings, including gurdwaras (Sikh temples), a mosque, a south Asian day centre for older people, and a south Asian women's centre.

Programme participants

Participants were recruited to the education programme first by response to letters of invitation to south Asian people with a diagnosis of type 2 diabetes, aged over 30 years, from GPs in the areas of Hounslow with the most substantial south Asian populations, and second by response to posters in community centres and places of worship, announcements at religious services, and an Asian radio feature. Those who responded were then given further information over the telephone, informed about the option of participating in research into the programme (as approved by the NHS Local Research Ethics Committee), notified by post as to the place and venue of forthcoming sessions, and asked to return a tear-off slip to confirm their attendance. Participants consented at the first session to allow their anonymised data to be analysed.

Hypotheses to be tested

It was hypothesised that the provision of a structured education programme, delivered in a language that could be easily understood by all participants, and adapted to community needs, would achieve significant change in health, knowledge and empowerment outcomes at 2, 6 and 12 months after participation.

The primary outcomes were the health measures of HbA_{1c}, blood pressure, BMI, total blood cholesterol, and waist circumference. Secondary outcome measures were diabetes knowledge and empowerment. The primary outcome measurements were chosen because these are well-established risk factors for diabetes and complications of diabetes, in particular ischaemic heart disease (Turner et al, 1998; Bosy-Westphal et al, 2006; Wild and Byrne, 2006).

Variables assessed

HbA_{1c} measurements were taken using an on-the-spot validated instrument, the DCA 2000+ (Bayer, Germany). Total cholesterol was also measured using an on-the-spot validated system, the Accutrend GC (Bio-stat Diagnostic Systems, Stockport). Blood pressure was measured with a monitor validated to the British Hypertension Society standards, the UA-767+ (P.M.S Instruments, Maidenhead),

Page points

1. As the modified knowledge questionnaire consisted of 27 questions, it was divided up into five mini-questionnaires, so that each week participants were only asked questions relating to the content of that session.
2. Attendance levels were relatively high: 75% of those who enrolled for the programme attended all five sessions, and 90% attended four out of five.
3. Evaluation of the programme during the first 6 months further revealed that, of the 96 participants, 83 found the sessions very useful and that 90 were confident that it would help them to improve their diabetes management and overall health.

with measurements taken as recommended by the Medicines and Healthcare products Regulatory Agency (2006) as far as practically possible. The Michigan Diabetes Knowledge Test (Fitzgerald et al, 1998) was adapted to alter questions relating only to type 1 diabetes and to incorporate south Asian diet and traditional remedies. It was then translated into Punjabi, Urdu and Hindi. The Michigan Diabetes Empowerment Scale-Short Form (Anderson et al, 2003), which is validated in English and was used in the X-PERT study, was also translated. Translations were checked for accuracy by volunteers in test groups. It was recognised that this was not a method for validating the translations, but it was felt adequate for the purposes of considering the acceptability of assessments to group members and the scope for them to improve their scores.

As the modified knowledge questionnaire consisted of 27 questions, it was divided up into five mini-questionnaires, so that each week participants were only asked questions relating to the content of that session. Thus, questions on cholesterol and food content were asked before discussion of saturated and unsaturated fats in relation to dietary content, and questions on diabetes medicines before the session on medication and alternative therapies.

At the end of each session the correct answers were shared with participants. By breaking down the questionnaire into weekly segments in this way it was hoped both to make it more acceptable to participants and to use it as a learning tool. At the 2- and 6-month follow-up sessions, participants were asked to fill in a summary knowledge questionnaire. As the empowerment questionnaire consisted of only eight questions, and it was felt important to assess participants' confidence to manage their diabetes before the education began, they were asked to complete all eight questions shortly after the commencement of the first session.

Results

Participation and acceptability of the programme

A total of 96 people enrolled in the programme during the first 6 months, which included a pilot phase, and provided service evaluation data on participation and acceptability. This data indicated that attendance levels were relatively high: 75% of those who enrolled on the programme attended all five sessions, and 90% attended four out of five.

The age of participants recorded during the first 6 months also provided a clear indication that the programme was well accepted by older people. In total, 70 out of the 96 participants were ≥60 years of age, and 30 were ≥70. Participation in relation to number of sessions was less than average at a local day centre for older people, with 10 out of 18 attending all five sessions, but this may have reflected health or mobility issues rather than lack of interest.

Gender of participants was also not an outcome variable, but more women than men attended the sessions during the first 6 months, with a ratio of approximately 60:40. This probably partly reflected the use of two women's groups and a women's centre, as well as the day centre, for the running of the sessions. A total of 80% of participants considered themselves Indian, and 14% Pakistani.

Evaluation of the programme during the first 6 months further revealed that, of the 96 participants, 83 found the sessions very useful and that 90 were confident that it would help them to improve their diabetes management and overall health. Six people were less certain it would help them, but none indicated that it was not useful and would not help them.

There were no apparent problems for participants in understanding the sessions, with respect either to language or educational content. A wide range of positive learning outcomes were reported – across lifestyle, medicines and risk factors – but the greatest number of comments related to healthy eating, healthy Asian cooking, and food content regarding fats, calories and the glycaemic index.

Suggestions for improving the sessions included the provision of written information that participants could take home and study or share with family members, and the inclusion of question-and-answer opportunities in every session.

Outcomes for knowledge and empowerment

Outcomes research data were available for 99 participants (those who began attending sessions after the pilot phase was complete up until the programme stopped recruiting) and provided both baseline and follow-up data.

Improvements in knowledge and empowerment were seen at first follow-up. The mean percentage of correctly answered knowledge questions increased from 55 to 71% (n=46), and for empowerment from 60 to 76% (n=32). However, in light of the not unanticipated difficulties engaging participants to complete questionnaires, with response rates being modest and the fact that changes were made to the unvalidated knowledge questionnaires between programmes, these trends can only be seen as indicative of improvement rather than as definitive evidence.

Outcomes for biomedical variables

Prior to enrolling in the programme, most participants had achieved desirable health outcomes with relation to the QOF (NHS Confederation and British Medical Association [BMA], 2003; NHS Employers, 2008). *Table 2* summarises results for the measured biomedical variables at baseline, 2 months and 6 months.

At baseline, the average HbA_{1c} for the group, of 7.0% (54 mmol/mol) was at an equivalent level to the post-education HbA_{1c} results recorded for the X-PERT trial (Deakin et al, 2006) and the UKPDS (UK Prospective Diabetes Study Group, 1998). Fewer than a quarter of all participants had an HbA_{1c} level >8% (>64 mmol/mol) at baseline, and this proportion reduced to 15% at 6 months. Similarly, the mean baseline BMI level of 27.27 kg/m^2 in the current study was well below both the mean level for the X-PERT intervention group at study end (30.6 kg/m^2; Deakin et al, 2006), and the baseline levels for intervention and control groups in Davies et al's (2008) trial of a similar programme (32.3 and 32.4 kg/m^2, respectively). Differences were of a similar order for waist circumference and blood pressure.

An instructive contrast was found between participants with a healthy HbA_{1c} level at baseline (a score of ≤6.5% [≤48 mmol/mol] was

Page points

1. Prior to enrolling in the programme, most participants had achieved desirable health outcomes with relation to the QOF.
2. Fewer than a quarter of all participants had an HbA_{1c} level >8% (>64 mmol/mol) at baseline, and this proportion reduced to 15% at 6 months.

Table 2. Mean results of the primary outcomes at follow-up at 2 months and 6 months.

	Baseline (SD)	2-month follow-up (SD)	Difference in means	Baseline (SD)	6-month follow-up (SD)	Difference in means
HbA_{1c} level (% [mmol/mol])	7.03 [53] (0.02)	6.92 [52] (0.01)	–0.11 [1.2] (P=0.44; 95% CI 0.02 – 0.24; n=87)	7.06 [54] (0.01)	6.94 [52] (0.01)	–0.13 [1.4] (P=0.13; 95% CI, –0.10 to 0.36; n=55)
Mean blood pressure (mmHg)	100.60 (13.22)	97.64 (12.53)	–2.96 (P=0.05; 95% CI, –0.70 to 6.62; n=40)	n/a	n/a	n/a
BMI (kg/m^2)	27.72 (3.86)	27.49 (3.87)	–0.24 (P<0.01*; 95% CI, 0.09 – 0.39; n=82)	27.18 (3.83)	27.05 (4.04)	–0.14 (P=0.14; 95% CI, –0.12 to 0.39; n=50)
Waist circumference (cm)	95.40 (9.17)	93.57 (8.42)	–1.83 (P=2.45; 95% CI, 0.98 – 2.68; n=80)	94.37 (9.29)	92.76 (8.39)	–1.61 (P<0.01*; 95% CI, 0.41 – 2.81; n=46)

*SD = standard deviation; CI = confidence interval. *Statistically significant difference. All figures have been rounded to 2 decimal places for presentation in this table.*

regarded as being within the healthy range), and those with an HbA_{1c} level greater than the healthy range at baseline. For the latter group (56 participants) a mean decrease in HbA_{1c} level from 7.56 to 7.31% (59 to 56 mmol/mol) was recorded at first follow-up, and for 38 participants with an HbA_{1c} level above normal at baseline who attended follow-up at 6 months, there was a mean HbA_{1c} decrease from 7.51 to 7.20% (58 to 55 mmol/mol). These improvements are comparable with the mean decrease from 7.7 to 7.4% (61 to 57 mmol/mol) achieved for the X-PERT intervention group at 4 months (whereas there was an increase from 7.7 to 7.8% [61 to 62 mmol/mol] in the control group) (Deakin et al, 2006).

By contrast, there were no trends of improvement at 2 and 6 months for those who had already achieved an HbA_{1c} level of ≤6.5% (≤48 mmol/mol) at enrolment, and their mean levels slightly increased, although remaining well within the predefined healthy range.

Limitations of biomedical data analysis

It was not possible to undertake follow-up assessments at 12 months, owing to funding pressures on the sponsoring organisation.

There were insufficient participants with valid blood pressure at 6 months to analyse for statistical significance, due to time constraints on a number of those attending (it was not possible to take repeat measures of their blood pressure at the end of the follow-up sessions).

Discussion

Participants had good glycaemic control at baseline. The further improvements in HbA_{1c} recorded for the majority of the group who were above the healthy 6.5% (48 mmol/mol) threshold at baseline seem likely to be due to their participation in the education sessions. By the same token, for those participants who had already achieved HbA_{1c} levels below 6.5% (48 mmol/mol) at baseline, there would have been less concern or incentive to reduce their risks with relation to this outcome variable still further, and other targets were likely to have been perceived as more relevant.

It is possible that mean biomedical outcomes improved further following the programme because of participants' continuing adherence to diabetes medication, and lifestyle guidance from primary care teams, rather than because of the structured education. A control group of similarly "well controlled" participants might, therefore, have recorded further

Allard S (2007) *Journal of Diabetes Nursing* **11**: 248–53
Anderson RM et al (2003) *Diabetes Care* **26**: 1641–3
Baradaran HR et al (2006) *BMC Public Health* **6**: 134
Bosy-Westphal A et al (2006) *Br J Nutr* **95**: 1212–20
Burden AC (2001) *Practitioner* **245**: 445–51
Choudhury SM et al (2009) *Diabet Med* **26**: 40–4
Davies MJ et al (2008) *BMJ* **336**: 491–5
Deakin TA et al (2006) *Diabet Med* **23**: 944–54
Deakin TA (undated) A synopsis of the key characteristics of Dr Trudi Deakin's X-PERT programme and associated randomised controlled trial [unpublished]
Department of Health (2001) *National Service Framework for Diabetes: Standards*. DH, London
Department of Health (2004) *Standards for Better Health*. DH, London
Department of Health, Diabetes UK (2005) *Structured Patient Education in Diabetes: Report from the Patient Education Working Group*. DH, London
Fitzgerald JT et al (1998) *Diabetes Care* **21**: 706–10
Gubb J, Li J (2008) *Checking-Up on Doctors. A Review of the Quality and Outcomes Framework for General Practitioners*. Civitas, London
Learning and Skills Council (undated) [untitled] Available at: http://bit.ly/dBiN6b (accessed 16.08.10)
Mather HM, Keen H (1985) *Br Med J* **291**: 1081–4
Medicines and Healthcare products Regulatory Agency (2006) *Device Bulletin. Blood Pressure Measurement Devices. DB2006(03)*. Department of Health, London
NICE (2003) *Guidance on the Use of Patient-education Models for Diabetes (Technology Appraisal 60)*. NICE, London.
NHS Confederation and British Medical Association (2003) *New GMS Contract 2003: Investing in General Practice. Annex A: Quality Indicators – Summary of Points*. DH, London
NHS Employers (2008) *QOF Changes and New Indicators for 2009/10*. Available at: http://bit.ly/QOF200910 (accessed 27.07.10)
Oldroyd J et al (2005) *Postgrad Med J* **81**: 486–90
Simmons D et al (1991) *Diabet Med* **8**: 651–6
Simpson L (2005) *Measuring Residential Segregation: Regional and City Profiles*. Centre for Census and Survey Research, University of Manchester.
Turner RC et al (1998) *BMJ* **316**: 823–8
UKPDS Group (1998) *Lancet* **352**: 837–53
Vyas A et al (2003) *Diabet Med* **20**: 1022–6
Wild SH, Byrne CD (2006) *BMJ* **333**: 1009–1011
Wilson E et al (1993) *Diabet Med* **10**: 177–180

improvements in the same way. However, this seems unlikely for two reasons.

First, since the programme was run from Autumn 2006 to Summer 2007, beginning two and a half years after QOF indicators had been introduced, the effect of the latter if any, on sufficiently motivated participants (such as the group in this study) to benefit from innovations in general practice care regimens would have been reflected in their pre-programme health results. It was between 2003 and 2005 that there was a "jump" in the percentage of people with diabetes in primary care achieving a desirable HbA_{1c} level of ≤7.5% (≤58 mmol/mol), and only small increases were recorded in subsequent years (Gubb and Li, 2008).

Second, given the time-lag between participants expressing an interest in the current programme and their attending, any newly diagnosed participants would be expected to have reduced HbA_{1c} levels, through education and therapy in primary care, prior to participating.

In light of the barriers to education for south Asian groups identified to-date, it seems reasonable to infer that participants' results improved following this programme because it was adapted to cultural needs with respect to language, literacy and accessibility. There are limitations to the ability to generalise, as with most research outputs on structured education programmes, given the self-selecting nature of participants. However, there do not seem to be any particular reasons that such a programme should not have similar benefit for UK south Asian populations elsewhere, given the community consultation that preceded its development, and its extensive promotion, including to 21 local south Asian organisations concerned with health and welfare, and to 43 general practices.

Conclusion

Modification of the X-PERT structured education programme to address cultural differences, combined with efforts to increase its accessibility, appear likely to make it well accepted by UK south Asian communities.

A service model in which trainees from south Asian communities are tutored and supervised to provide structured education is practicable and cost-effective. This model is being further developed at the study site.

A modified X-PERT programme is associated with trends of health improvement for south Asian participants, who believe that the programme is helping them to make such improvement and are confident that it will help them manage their diabetes.

More information is required about what attracts participants to attend modified programmes and what educational needs they have, and what kinds of options for change are of most interest to them. It is clear from the current study that many participants will have been able to reduce risks and improve health, often with the assistance of primary healthcare services. What it is that such groups may be seeking – in addition to improvements that primary care can offer – is important to clarify. For the group in the present study, it would appear that diet and lifestyle information or guidance was of particular benefit within the wider range of topics covered by the programme.

Bearing in mind the NICE (2003) definition of structured education as a graded programme, it is possible that different types of course, of different duration and with different topic emphases, customised to reflect areas of prior knowledge and interests among potential participants, may be appropriate. ■

Ripanjit Gill is a Diabetes Lay Educator, Homerton Hospital; Jacob Leveridge is Biomedical Ethics and Medical Humanities Advisor, The Wellcome Trust; Rupindar Sahota is a Diabetes Specialist Dietitian, Hounslow and Richmond Community Healthcare, Provider Arm NHS Hounslow; Sarvesh Saini is a GP, St Margarets Medical Practice, Twickenham; Dylan Tomlinson is Evidence Reviews Manager, Hounslow PCT, Hounslow, London. Jacob Leveridge's involvement in the project pre-dates his current appointment at The Wellcome Trust and the project is neither funded by, nor linked to, The Wellcome Trust.