

# Type 2 Diabetes Education: Patient and Public Engagement

# 2018

Results and recommendations from research undertaken between February and October 2018 with healthcare professionals, patients and members of the public, aiming to better understand the needs and preferences of our local population when developing strategies to increase uptake of structured education across Airedale, Wharfedale and Craven.

Diabetes Structured Education Team, Airedale NHS Foundation Trust

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Queries to: [louise.nash@anhst.nhs.uk](mailto:louise.nash@anhst.nhs.uk) or [jane.brophy@anhst.nhs.uk](mailto:jane.brophy@anhst.nhs.uk)

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## 1. Executive Summary

NHS England has provided funding to the Airedale, Wharfedale and Craven (AWC) Clinical Commissioning Group (CCG) to improve uptake of structured education. A Patient and Public Engagement (PPE) Project has been carried out by the Diabetes Structured Education at Airedale NHS Foundation Trust in order to better understand the needs of the local population and to factor recommendations into strategies aiming to increase uptake of structured education. Findings are summarised within this report which focusses on:

- Exploring barriers and enablers
- Exploring appropriate language
- Finding out what people want to learn and how

Thoughts were gathered from 25 local healthcare professionals (HCPs) and 118 local patients and members of the public from a range of demographic groups, via interviews, focus groups and questionnaires, and considered alongside national guidelines and research in order to identify key themes and priorities and make recommendations to the Structured Education project team.

Recommendations are in Section 11. Most of these have already been implemented or have been factored into existing plans.

## **2. Introduction**

### **Background**

The uptake of structured education for people living in AWC has historically been poor. Latest data shows that only 43% of patients with Type 2 Diabetes take up the offer of attendance on a structured education course. Specific populations where attendance has been low have been the local community in Keighley with a high proportion of South Asian population and patients who are working age and are not available during the working day when structured education is available. NHS England has since provided funding to the AWC CCG to improve uptake of structured education.

This report summarises findings from the Patient and Public Engagement (PPE) Project and provides recommendations.

### **PPE Project Aim**

To understand the needs, views and preferences of local population groups regarding structured education.

### **PPE Project Objectives**

- Explore barriers and enablers
- Explore appropriate language
- Find out what people want to learn and how

PPE Project findings and recommendations will feed into the Diabetes Structured Education team's strategy for improving uptake of patient education.

### 3. Summary of information sources

In addition to a review of national data, thoughts and opinions were gathered from 25 HCPs and 100 local patients and members of the public.

| National guidelines and research   | Population group          | Method                | Numbers |
|--|---------------------------|-----------------------|---------|
| Evidence-based nutrition guidelines for the prevention and management of diabetes. March 2018, Section 8 (Diabetes UK) | BME                       | Research              |         |
| Language matters. Language and diabetes. June 2018 (NHS England)   | Diabetes patients England | Research              |         |
| Diabetes UK Bright Ideas #2 Tower Hamlets  | BME Tower Hamlets         | Best practice example |         |

| Local knowledge and research   | Population group     | Method                   | Numbers  |
|--|----------------------|--------------------------|--|
| ANHST Report on barriers to engagement with adult diabetes structured education in AWC           | AWC                  | Electronic questionnaire | 18 GPs and other HCPs  |
| Enhanced Diabetes and Specialist Podiatry Service Engagement Event 23.11.16 – Summary of Outputs | AWC                  | Discussion forum         |  |
| “Spicing it up” – Engaging the BAME community in Bradford  | South Asian Bradford | Best practice example    | 1 Dietetic Team  |
| HCP feedback   | South Asian Bradford | Interviews               | 2 Dietitians<br>1 Diabetes Nurse                             |
| HCP feedback   | South Asian AWC      | Interviews               | 1 Dietitian<br>1 Language Support Worker<br>1 Diabetes Nurse |

| Patients and public  | Population group   | Method         | Numbers                           |
|--|--|----------------|-----------------------------------|
| Exploring thoughts about SE – X-PERT group patients  | Mixed gender, mixed ethnicity                                  | Focus group x2 | 13 patients<br>4 companions       |
| Exploring local learning needs and preferences with local populations (AGH L4 clinic, Keighley patients, Ilkley members of the public) | Mixed gender, mixed ethnicity                                  | Questionnaire  | 50 patients/<br>members of public |
| Exploring local learning needs and preferences with local populations (Roshni Ghar, Highfield Centre)                                  | South Asian ladies: mostly Urdu/Punjabi speakers, some Bengali | Focus group x5 | 36 participants                   |
| Exploring local learning needs and preferences with local populations (Sangat Centre)  | South Asian men, Urdu/Punjabi speakers                         | Focus group x1 | 15 participants                   |

## 4. National guidelines and research

NHS England's "Language Matters" provides guidance on the use of language when talking about diabetes, including practical application. It offers some principles for good practice for interactions between HCPs and people living with diabetes:

- use language that is free from judgment or negative connotations, particularly trying to avoid the threat of long-term consequences or scolding
- collaborative and engaging, rather than authoritarian or controlling
- avoid language which attributes responsibility or blame to a person for the development of their diabetes or its consequences
- avoid language that infers generalisations, stereotypes or prejudices, or links one individual with previous experience of others of a similar background or situation
- Use empathic language style which seeks to ascertain a person's point of view of their condition, rather than assume

Diabetes UK's current nutritional guidelines contain a section "Considerations in ethnic minority groups." This section highlights that ethnic minority groups often face significant barriers to accessing healthcare because of linguistic and cultural differences, poor healthy literacy, low socio-economic position and their migrant status. As a result, they often have poor diabetes knowledge, worse glycaemic control and higher rates of diabetes complications compared with the general population. It highlights a lack of cultural knowledge and awareness amongst HCPs and a failure to account for cultural beliefs and practices in generic education. The section summarises themes identified in research with South Asian communities:

- Language and communication discordance is a significant barrier to receiving and understanding diabetes education
- Preference for physician's guidance over self-management
- Lack of culturally-specific details on South Asian foods within dietary advice
- Misconceptions on components of traditional diet for people with diabetes
- Lack of gender specific exercise facilities
- Fear of injury or worsening health with exercise
- Preference for folk and traditional remedies over diabetes medication management
- Facilitators include:
  - trust in care providers
  - use of culturally appropriate exercise and dietary advice
  - increasing family involvement

Diabetes UK makes the following recommendations regarding education for South Asian communities:

- bilingual/bicultural professional educators or non-professional workers to provide the education or support delivery
- delivery in preferred language, including all materials
- weekly group sessions followed by regular telephone calls for reinforcement
- When recruiting participants, personal methods such as referral through clinics or telephone calls are likely to be most effective
- Particular effort should be made to recruit people with poor glycaemic control
- Pilot interventions to assess effectiveness and allow participant feedback
- Teaching about dietary change by modifying ethnic foods and recipes

- Teaching activity change using culturally appropriate activities eg dancing and walking
- Attendance by family member to elicit home-based support
- Use of visual aids to tailor to low-literacy needs
- Inclusion of advice regarding diet, activity and medication management during fasting

In Tower Hamlets the main ethnic group is Bangladeshi, although the local population comprises people from over 200 different countries and over 43% born outside the UK. Diabetes centre staff have increased uptake of diabetes education by:

- Advertising courses in local GP surgeries
- Being visible in the community, eg regularly delivering Ramadan education sessions
- Making it easy to book on to a course – those referred receive a letter with an appointment date, they then receive a telephone call explaining the course. They can confirm, alter the date or choose not to attend.
- Holding sessions on weekdays and early evenings in the diabetes centre, GP surgeries and occasionally community centres, with tea and coffee
- Telephone reminders before sessions

## 5. Local knowledge and research

Analysis of 2015 data found that uptake of SE was poor across the board. Keighley fared worst, highlighting a particular need to focus on the South Asian population; but the problem is not isolated to Keighley, there is a need to engage with a range of population groups.

| <b>% of patients attending SE within 12 months of diagnosis</b> | <b>Practices</b>   | <b>Comments</b>  |
|---|--|--|
| 0%  | Ilkley & Wharfedale<br>Oakworth<br>North Street  | 2 Keighley practices<br>1 Ilkley practice<br>Large South Asian population                  |
| 0-15%   | Dyneley House<br>Ling House<br>Farfield<br>Holycroft<br>Kilmeny<br>Grassington                         | 4 Keighley practices<br>2 Skipton/Craven practices<br>South Asian population at Ling House |
| 15-25%  | Cross Hills<br>Fisher<br>Silsden & Steeton<br>Grange Park<br>Addingham<br>Ilkley Moor Medical Practice | 2 Skipton/Craven practices<br>4 Ilkley/Wharfedale practices                                |
| 25-50%  | Addingham  | Small numbers in data were rounded, so may be inaccurate                                   |

Prior to the project starting, research with local HCPs had identified the following:

### Reasons why attendance is low – HCP views

- Patients unaware of education programmes, or how they might be relevant to them.
- Time: X-PERT requires 6 half days away from other commitments such as work
- Aversion to groups: the prospect of attending a meeting and discussing private issues
- Cultural beliefs can cause people to reject structured education
- Differing populations, from rural communities to a large South Asian population – but a uniform structured education offer which does not flex to population needs
- Lack of positivity and enthusiasm from HCPs about the benefits of SE; some HCPs do not see education as an essential part of diabetes care.

### Feedback from patients on non-attendance and what could help improve attendance

- Forgetting about the course if it is booked quite far in advance
- Not being able to attend because of work or childcare commitments on the day
- Not being able to commit to so many hours of structured education
- Being uncomfortable with being “taught”, like being back in school

### Learning from our colleagues in Bradford

Diabetes specialists in Bradford have worked with their local South Asian community to improve engagement. They developed the following teaching tools:

- A pack of low fat authentic versions of traditional South Asian recipes
- Photographs of South Asian foods to support carbohydrate awareness and portion size discussion
- Recipes sourced from the Islami nutrition website, a local cookery club and staff from the community, modified to meet healthy eating guidance on fat and salt – which evaluated well

- Mums Matter project – 1.5 hour education session with lunch and crèche facilities for 6 weeks postnatally, delivered at local children’s centre, emphasis on weight loss, healthy eating, portion control and physical activity – led to improvements in diet quality, exercise and mood
- DiCE Asian Taster session – male and female groups, majority of patients went on to sign up to full week course. (DiCE is Bradford’s equivalent of X-PERT.)

The things they found worked for them included:

- Making sure education is culturally appropriate and tailored to local population – and using the community to find out what that means
- South Asian language speakers invaluable
- Telephone engagement improved attendance
- Utilising a familiar environment
- Providing healthy meals is an incentive

The following themes came out of interviews with two diabetes dietitians and one diabetes nurse who have worked with the South Asian population in Bradford:

| Problems   | What worked well   |
|--|--|
| <ul style="list-style-type: none"> <li>• Participants want us to go to them</li> <li>• Participants want a bus and meal to encourage attendance, this wasn’t possible</li> <li>• People often turned up part way through or left early</li> <li>• Need to consider prayer times – afternoon sessions better attended in summer than winter as prayer times are closer together in winter months</li> <li>• Delivering via interpreter takes longer. Need trained interpreters who can do group facilitation.</li> <li>• Some of population don’t read so need less words, more pictures</li> </ul> | <ul style="list-style-type: none"> <li>• Holding sessions at children’s centre where lunch and crèche could be provided</li> <li>• GPs told participants to attend “an appointment about their diabetes” which would last an hour</li> <li>• Cultural tailoring of sessions, resources, information sheets, food models</li> <li>• Photographs of meals</li> <li>• Delivery by South Asian dietitian</li> <li>• Separate male and female groups</li> <li>• Offering social element and refreshments – fruit is acceptable</li> </ul> |

### Learning from our colleagues in AWC

The following themes came out of interviews with one diabetes dietitian, one diabetes nurse and one language support worker who have worked with the South Asian population in AWC:

| Problems  | What worked well   |
|---|--|
| <ul style="list-style-type: none"> <li>• Hard to recruit to</li> <li>• Poor attendance</li> <li>• Participants often late and brought friends</li> <li>• Attendees didn’t always understand Western beliefs about how the body works, eg carbe metabolism</li> <li>• Kept needing to go back to basics</li> <li>• Difficult to get people to identify goals and changes</li> <li>• Often ran out of time as people needed more explanation</li> </ul> | <ul style="list-style-type: none"> <li>• Attendees brought in own chapatis</li> <li>• Weighed portions of rice</li> <li>• South Asian food pics</li> <li>• Used North Street surgery – patients knew it so it worked well</li> </ul> |

In June 2016 a local engagement event explored what a successful future would look like, identifying along the way. The following wishes and themes were identified of relevance to structured education provision:

|  |  |
|--|--|
| <ul style="list-style-type: none"> <li>• Education for all diabetes patients, at all levels</li> <li>• Chat forum for education / support</li> <li>• Language and culturally appropriate</li> <li>• Empowerment; self-care</li> <li>• Offer evenings and education in the community</li> </ul> | <ul style="list-style-type: none"> <li>• Patient ownership and motivation</li> <li>• Preventing complications</li> <li>• Working with families</li> <li>• Diabetes specialists coming to surgery</li> <li>• Support</li> </ul> |
|--|--|

## 6. Focus Groups (X-PERT participants)

### PURPOSE OF FOCUS GROUPS

To explore:

- what made people sign up to X-PERT
- how we can encourage other people to book on

In order to better understand of our local population, to help us improve access to structured education for patients with type 2 diabetes throughout Airedale, Wharfedale and Craven (AWC), with a view to increasing uptake.

### PARTICIPANTS

|                      | Group 1  | Group 2   |
|----------------------|--|---|
| <b>Date</b>          | 27.03.2018   | 08.05.2018  |
| <b>Location</b>      | Sainsbury's Keighley   | Dyneley House Skipton   |
| <b>Facilitator</b>   | Jane Brophy  | Louise Nash   |
| <b>Participants</b>  | 10 (8 participants, 2 companions)                            | 7 (5 participants, 2 companions)  |
| <b>Group profile</b> | X-PERT GROUP participants<br>Mixed gender<br>Mixed ethnicity | X-PERT GROUP participants<br>3 female, 4 male<br>All white<br>Age group mostly > 50 |

### SUMMARY RESULTS

#### Q1: What made you sign up to X-PERT in the first place?

| Group 1  | Group 2   |
|--|---|
| <ul style="list-style-type: none"> <li>• After doctor made 2 or 3 referrals</li> <li>• All agreed doctors referral was crucial</li> <li>• Via sister who was diagnosed 8 years ago</li> <li>• Took a long time to get place on the course</li> <li>• Might not have Diabetes if had been offered the course earlier</li> <li>• Had diabetes for 8 years and was not offered</li> </ul> | <ul style="list-style-type: none"> <li>• My GP / other HCP recommended it (x5)</li> <li>• I wanted to learn more</li> <li>• I was concerned about my diet and portion sizes</li> <li>• I saw an advert in the GP surgery</li> <li>• Diabetes runs in the family so I'm particularly interested</li> <li>• I wasn't managing it by myself</li> <li>• Previously did "Empower" course in Colne but felt I needed more</li> <li>• I wanted to lose weight</li> </ul> |

#### Q2: What terms would be more appealing than "Structured Education"?

| Group 1   | Group 2  |
|---|--|
| <ul style="list-style-type: none"> <li>• Not heard the term "Structured Education" – all participants</li> <li>• Well it needs to be structured</li> <li>• Liked the idea of a "short-course"</li> <li>• Make it tailored to individuals</li> </ul> | <ul style="list-style-type: none"> <li>• "Course" – to help you to know what to eat (x4)</li> <li>• "X-PERT" is offputting – too intense?</li> <li>• Sessions</li> <li>• Small group discussions</li> <li>• Support group</li> </ul> |

#### Q3: Suggested names for type 2 short course

Not included here – not relevant.

#### Q4: Is there anything else generally you think we should think about when setting up new courses?

| Group 1  | Group 2   |
|--|---|
| <ul style="list-style-type: none"><li>• It takes time for people to change</li><li>• Short- course may not be long enough</li><li>• Person who attends has to be ready to change</li><li>• Food packaging should indicate if “diabetic-friendly”</li><li>• Lay educators could help as would be able to simplify a complex topic</li><li>• Short-course would be good as an introduction or taster</li><li>• Doctors surgery would be a good place to have the introductory course</li></ul> | <ul style="list-style-type: none"><li>• 6 weeks too long but need more than a half day</li><li>• Offer evening classes</li><li>• Target younger end</li><li>• Work with secondary schools</li><li>• Limit numbers – max 12</li><li>• Stress it’s ok to bring partner</li><li>• Location and transport are important</li><li>• “Free information for your health / your life to arm you with knowledge to improve and extend your quality of life”</li></ul> |

#### Other comments:

| Group 1  | Group 2  |
|--|--|
| <ul style="list-style-type: none"><li>• Confusion with Bradford and Keighley phone numbers</li><li>• Assessment needed for suitability</li><li>• Need for brochure – meals/recipe ideas</li><li>• Need to know what to eat?</li><li>• Peer support needed to hand-hold in between doing course and after</li><li>• Needs to work for those who don’t need to lose weight</li><li>• Lots of compliments for X-PERT course and educators</li></ul> | <ul style="list-style-type: none"><li>• Problems with referral processes – not getting referred when asked? Not receiving confirmation?</li><li>• Received a letter to say not responded</li><li>• Face-to-face is better than a leaflet / book</li><li>• Enjoy group discussion and mutual understanding / experience – you are not alone</li><li>• Circular layout works better than classroom style</li></ul> |

## CONCLUSIONS and RECOMMENDATIONS

1. Encouraging GPs and other HCPs to encourage structured education is key to improving uptake.
2. There needs to be a system for re-offering structured education.
3. Referrers need to recognise “hooks”, eg family history, wanting to lose weight, asking questions, not managing.
4. There is a need for a course of less than 6 weeks but more than 2 hours duration.
5. Lay educators could enhance delivery.
6. Permission to bring a partner is important.
7. New courses need to include “out of hours” provision, a number of locations and transport.
8. Use the term “course” rather than “structured education”

Points 1, 2, 5, 6 and 7 are already factored into current plans to improve uptake of structured education.

## NEXT STEPS

Alongside other data being gathered as part of our needs assessment, consider the feasibility of incorporating these recommendations into our plans, particularly recommendations 3, 4 and 8.

Louise Nash 9 May 2018

## 7. Focus Groups (South Asian ladies)

### PURPOSE OF FOCUS GROUPS

To explore

- how we can encourage ladies within the South Asian community to attend our courses
- what we need to consider in developing structured education provision for South Asian community

### PARTICIPANTS

Total 36 participants. Of these, 22 had been diagnosed with diabetes. Other participants had pre diabetes or were living with / caring for someone with diabetes. Further information below:

|                      | Group 1  | Group 2   | Group 3   | Group 4  | Group 5   |
|----------------------|--|---|---|--|---|
| <b>Date</b>          | 25.06.18   | 26.06.18  | 29.06.18  | 18.07.18   | 19.07.18  |
| <b>Location</b>      | Roshni Ghar, Keighley  | Roshni Ghar, Keighley   | Roshni Ghar, Keighley   | Roshni Ghar, Keighley  | Highfield Centre, Keighley  |
| <b>Facilitator</b>   | Louise Nash<br>Jane Brophy   | Jane Brophy   | Louise Nash   | Louise Nash  | Louise Nash   |
| <b>Participants</b>  | 14   | 5   | 4   | 2  | 12  |
| <b>Group profile</b> | Established mental health group for South Asian ladies<br>10 Urdu/Punjabi<br>2 Bengali<br>10 diabetes<br>2 pre-diabetes<br>Age range 30/40 – 60/70 | Established mental health group for South Asian ladies<br>5 Urdu/Punjabi<br>2 diabetes<br>5 family history<br>Younger age range | Established mental health group for South Asian ladies<br>4 Urdu/Punjabi<br>3 diabetes<br>1 family history<br>All over 60 | Established mental health group for South Asian ladies<br>2 Bengali<br>2 diabetes<br>All over 50 | Established group for South Asian ladies<br>11 Urdu/Punjabi<br>5 diabetes<br>6 family history<br>Age 30 – 70+ |

### SUMMARY RESULTS

#### Q1: What do you know about the courses available at the moment for people with diabetes?

Two ladies (Groups 1 and 2) had attended 6 week courses (X-PERT?). Another lady (Group 5) thought she'd been invited to something but hadn't attended "because I'm lazy." The remaining ladies were not aware of any courses and did not recall having been told about a course. They talked about check-ups with healthcare professionals.

#### Q2: We're planning to put on some courses for groups of people with diabetes. What do you need to make you want to attend?

| Groups 1-4 (Roshni Ghar)  | Group 5 (Highfield)  |
|---|--|
| <ul style="list-style-type: none"> <li>• Hold course at Roshni Ghar, fit with existing group meeting times (23)</li> <li>• GP centre better as easy to attend (1)</li> <li>• Provide fruit (1)</li> <li>• Deliver in South Asian language (19):<br/>- Urdu / Punjabi (17)<br/>- Bengali (2)</li> <li>• Visual content eg pictures, portion sizes (14)</li> <li>• Make it relevant to South Asian diet (14)</li> <li>• 2 hour session with refreshment break (14)</li> </ul> | <ul style="list-style-type: none"> <li>• Hold course at Highfield, fit with existing group meeting times (11)</li> <li>• Ladies only courses (11)</li> <li>• Transport is a barrier (1)</li> <li>• Men don't see health as important – ladies do the cooking so more important to focus on them (7)</li> <li>• Welcoming approach, lots of praise and encouragement (1)</li> </ul> |

- I wouldn't attend, I see DSN, know all I need to (1)
- Very keen, want to know how to manage re' diet (4)

**Q3: The course we have at the moment focusses more on Western culture and foods. It covers all sorts of topics such as: how diabetes affects the body, how what we eat affects diabetes and how to lose weight to improve diabetes. Are there any topics relevant to your community that you think we should include in a course?**

| <b>Groups 1-4 (Roshni Ghar)</b>   | <b>Group 5 (Highfield)</b>   |
|---|--|
| <ul style="list-style-type: none"> <li>• Explain which foods to eat / avoid and why (19)</li> <li>• How and why diabetes affects the body (eye sight, feet) (14)</li> <li>• Hypo awareness (symptoms and treatment) (16)</li> <li>• Over correcting hypo (1)</li> <li>• What to eat during Ramadan (18)</li> <li>• Importance of exercise (2)</li> <li>• Healthy eating for children to prevent diabetes (5)</li> <li>• What to do about bloated stomach (1)</li> <li>• How to manage pain in legs (1)</li> <li>• Vegetarian options (4)</li> <li>• Healthier cooking methods (eg baked samosa) (4)</li> <li>• Symptom awareness (4)</li> <li>• Signs to look out for re progression, eg eyesight (4)</li> <li>• What id you don't look after your body? (2)</li> <li>• Leaflets in Urdu or pictorial (2)</li> <li>• Blood glucose testing (1)</li> </ul> | <ul style="list-style-type: none"> <li>• Explain which foods to eat / avoid and why, eg mangoes, Asian tea (4)</li> <li>• Portion control (4)</li> <li>• What to eat during Ramadan (11)</li> <li>• How does fasting affect the body? (4)</li> <li>• Pros and cons of fasting (4)</li> <li>• Do you need to fast during Ramadan? (7)</li> <li>• Risk factors for developing diabetes, eg family history (4)</li> <li>• Symptom awareness (1)</li> <li>• Practical demo, eg "cook and eat" – maybe as a separate session (1)</li> <li>• Healthier cooking methods (eg less oil) (4)</li> <li>• Daily / weekly food plan (1)</li> <li>• Diabetes prevention (7)</li> <li>• Ideas for exercise with limited mobility (7)</li> <li>• How to motivate – rewards for doing well (7)</li> </ul> |

**Q4: Our Western course is called "Diabetes Made Easy." Would this work for a South Asian course? Or do you have any other ideas for a good name which would make you want to attend?**

All attendees liked the name "Diabetes Made Easy" and felt it would translate. No other ideas were put forward.

**Q5: Is there anything else you think we should think about when we set up a course**

All comments added at the end of the sessions have been captured within Q2 and Q3.

## CONCLUSIONS and RECOMMENDATIONS

These ladies are more likely to attend a course if it is held at their regular group sessions, delivered in appropriate language (mainly Urdu / Punjabi), relevant to South Asian diet and culture with high visual content, a ladies only course and ideally a short 2 hour session with a refreshment break.

Below are the topics of most interest to these ladies, to be considered when developing the course:

- Foods to eat and avoid
- Symptoms of diabetes
- Diabetes progression and signs of progression
- Ramadan – what to eat and fasting
- Diabetes prevention
- Healthy eating for children
- Healthy cooking methods
- Ideas for exercise when mobility is limited
- Motivation / rewards for doing well

## NEXT STEPS

Alongside other data being gathered as part of our needs assessment, consider the feasibility of incorporating these recommendations into our plans in developing our South Asian Type 2 Diabetes courses.

Louise Nash July 2018

## 8. Focus Group (South Asian men)

### PURPOSE OF FOCUS GROUPS

To explore

- how we can encourage men within the South Asian community to attend our courses
- what we need to consider in developing structured education provision for South Asian community

### PARTICIPANTS

15 male participants, all of Pakistani ethnicity, age range 40 – 70+. Focus group carried out at Sangat Centre, Keighley on 15 October 2018.

### SUMMARY RESULTS

#### **Q1: What do you know about the courses available at the moment for people with diabetes?**

Most were unaware of X-PERT, it had not been offered to them. Some said they thought they may have been offered courses but they don't read letters properly.

Only one participant recalled being offered X-PERT. Didn't attend all 6 sessions due to time commitment and other appointments.

One participant had attended a course over 25 years ago but unsure which course.

#### **Q2: We're planning to put on some courses for groups of people with diabetes. Do you think it would be best to deliver them at a set time or as drop-in sessions where people can turn up and leave when they like?**

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##### **Ideas**

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- Courses delivered in existing groups, eg Sangat Centre meeting times
  - Monday – Thursday best. Avoid Fridays due to prayers.
  - Fixed times preferred. 10.00 – 12.00 most suitable to avoid afternoon prayer times (13.)
  - Group felt drop-in sessions would be disruptive and not conducive to effective uptake of information.
  - Preference for learning in a group environment in larger groups.
- 

#### **Q3: We're planning to put on some courses for groups of people with diabetes. What do we need to do to make you want to attend?**

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##### **Ideas**

---

- Separate men and women sessions (13)
  - Courses delivered with language support
  - Courses should include South Asian content
  - Refreshments (tea/coffee) welcome
  - Transport is not a problem as Sangat Centre has its own minibus
  - Participants willing to attend courses at Sangat Centre or North Street Surgery
- 

#### **Q4: Out of all the ideas in Q3, which do you think are most important?**

---

##### **Ideas**

---

- Time of day is most important
  - Good information
  - Positive outcomes, eg "get better"
  - Ability to implement messages from courses and maintain changes in order to "stay well"
-

**Q5: The course we have at the moment focusses more on Western culture and foods. It covers all sorts of topics such as: how diabetes affects the body, how what we eat affects diabetes and how to lose weight to improve diabetes. Are there any topics relevant to your community that you think we should include in a course?**

---

### Ideas

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- How much physical exercise is recommended, eg walking duration
  - Diet and what to eat relevant to South Asian community
  - How to stay well and prevent progression of illness
  - Medication
  - Ramadan and fasting. Most participants reported fasting against the advice of their GP / Health professionals. They wanted information on safe, healthy fasting because they felt very strongly that they would fast despite medical advice to the contrary. Group were aware that their religion does permit them to abstain from fasting but they still chose to do it.
  - Most of the group were not interested in learning about healthier cooking methods. They suggested offering 'Healthier cooking method' classes to their women folk who do the cooking. (15)
  - Some participants would like information around healthier cooking methods as they do cook for themselves.
  - Cooking for everyone in the household as opposed to cooking separate meals for those with diabetes.
  - Information on how to live well whilst abroad eg. Pakistan, Saudi Arabia
  - Blood pressure, cholesterol. Incorporate checks into courses.
  - Smoking / chewing tobacco
  - Exercise (15)
- 

**Q6: Our Western course is called "Diabetes Made Easy." Would this work for a South Asian course? Or do you have any other ideas for a good name which would make you want to attend?**

Participants were happy with "Diabetes Made Easy" – not too concerned about name of course.

Alternative name suggestions: "Diabetes live easy" "Better off without diabetes"

**Q7: Is there anything else you think we should think about when we set up a course**

- Blood test results: HbA1c and finger prick and what the difference was.
- Injections: why they were needed and why sometimes both injections and oral medication was needed. Participants were under the impression that injections were sufficient for managing their diabetes.
- Sharing of ideas between the group should be incorporated into the courses.

## CONCLUSIONS and RECOMMENDATIONS

These men are more likely to attend a course if it is held outside prayer times (avoid Fridays, avoid afternoons), delivered at one of their regular group sessions or at North Street, delivered in appropriate language and culturally appropriate. They wanted separate gender groups and would prefer a formal group with set-times to drop-in sessions. Below are the topics of most interest to these men, to be considered when developing the course:

- |                        |  |
|------------------------|--|
| • Exercise guidance    | • How to live well while abroad                        |
| • Diet and what to eat | • Blood pressure and cholesterol checks within courses |
| • Medication           | • Smoking / tobacco                                    |
| • Ramadan and fasting  | • Sharing of ideas                                     |
| • Blood test results   |  |

## NEXT STEPS

Alongside other data being gathered as part of our needs assessment, consider the feasibility of incorporating these recommendations into our plans in developing our South Asian Type 2 Diabetes courses.

Focus Group data gathered by Shamim Akhtar and Jane Brophy October 2018

## 9. Questionnaires

### Questionnaire Feedback gathered from Type 2 diabetes patients April – June 2018

#### PURPOSE OF QUESTIONNAIRE

To explore:

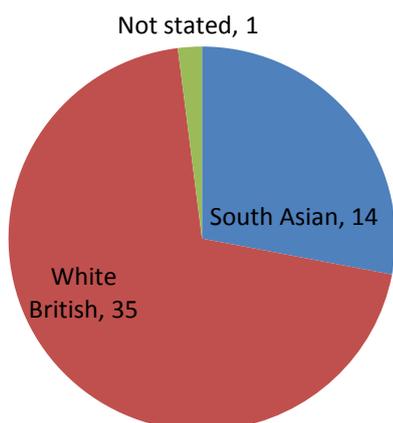
- People's learning preferences for diabetes education
- Preferences on dates, times and venues

To better understand the preferences of our local population so we can improve access to structured education for patients with type 2 diabetes throughout Airedale, Wharfedale and Craven (AWC).

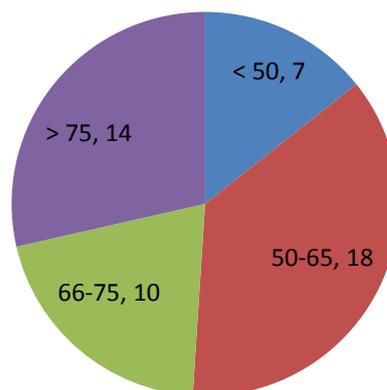
#### PARTICIPANTS

- 50 participants in total, all of whom have a diagnosis of Type 2 Diabetes:
  - 29 AGH Level 4 patients
  - 10 North Street Level 2 patients (with help from Language Support Worker)
  - 2 Keighley Health Centre general clinic patients
  - 2 Farfield Level 2 patients
  - 7 Clarke Foley customers

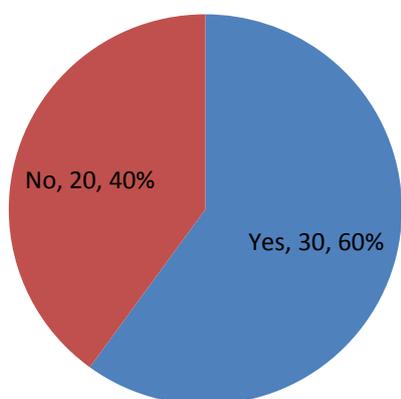
#### Ethnicity



#### Age

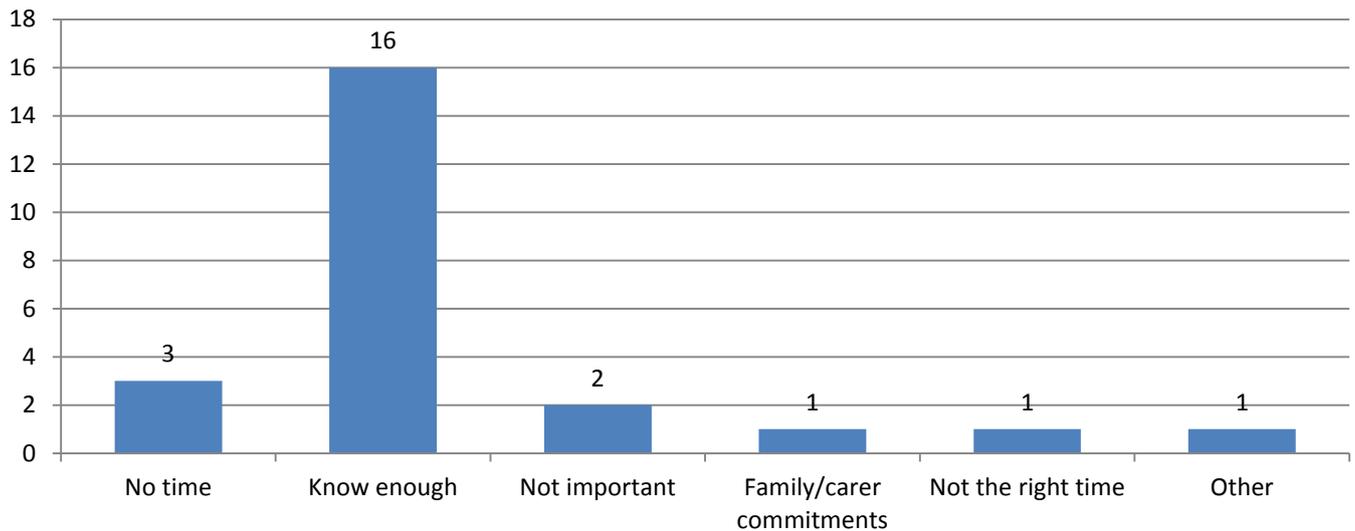


#### Q1. Would you like to learn more about your diabetes?



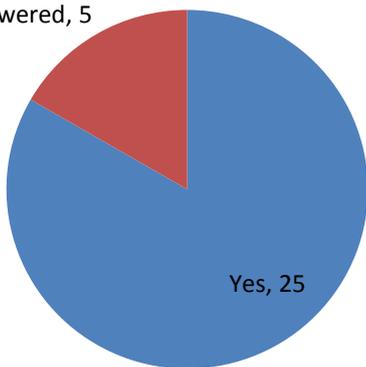
|                  | Yes | No |
|------------------|-----|----|
| <b>Setting</b>   |     |    |
| AGH L4           | 16  | 13 |
| KHC              | 2   | -  |
| North Street     | 5   | 5  |
| Farfield         | 1   | 1  |
| Clarke Foley     | 6   | 1  |
| <b>Ethnicity</b> |     |    |
| White British    | 21  | 14 |
| South Asian      | 9   | 5  |
| Not stated       |     | 1  |

**Q2. If “No to Q1: What’s the reason for that? (tick all that apply)**



**Q3: Would you be happy to join a group of other people with diabetes to learn more, in a time and place that suits you?**

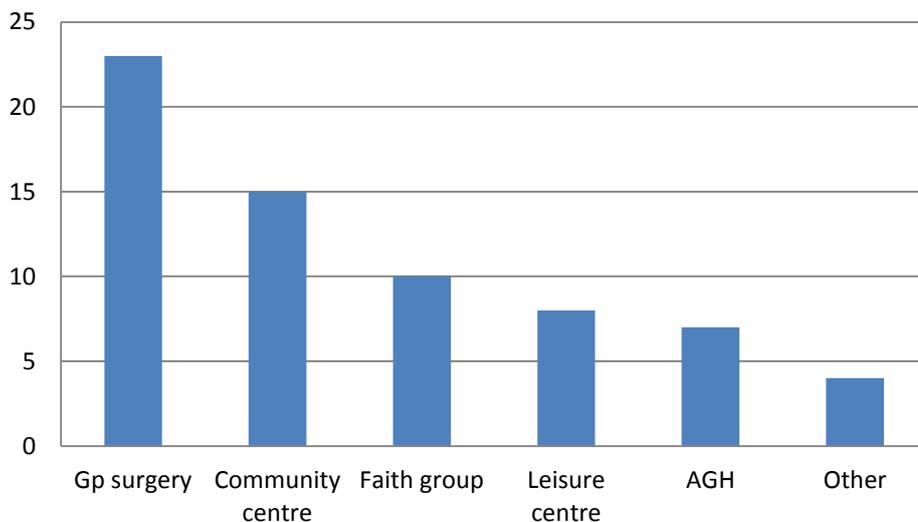
No or not answered, 5



**Q4: If “No” to Q3, what’s the reason for that?**

The answers were mostly to do with practicalities such as transport and time rather than being unwilling to join a group.

**Q5a) Where would you be happy to go? (can tick more than one)**



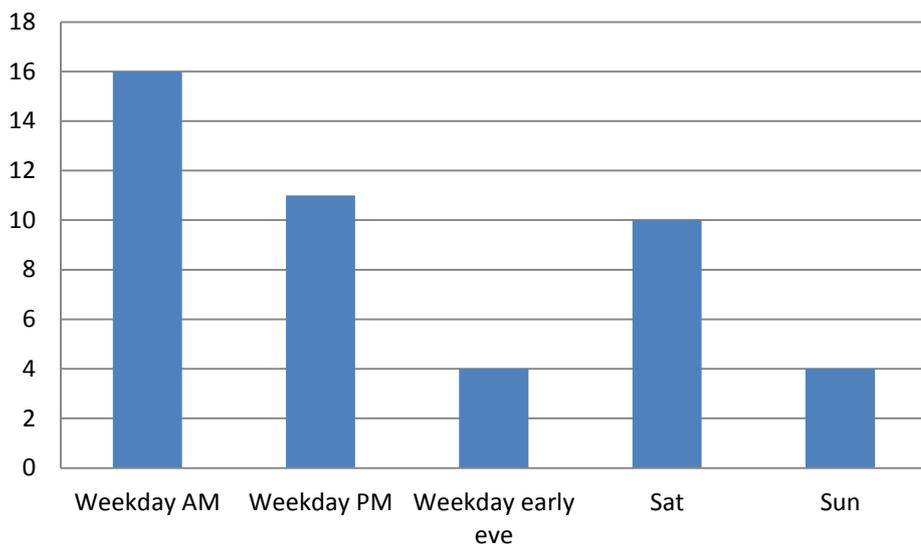
Of the 9 South Asian patients who wanted to learn more about diabetes, options selected were:

- GP surgery: 5
- Community centre: 4

All those selecting the other options were from the White British group.

NB AGH wasn’t a standard option, it came out during conversation, so AGH numbers might be higher.

**Q5b) When would be a good time for you? (can tick more than one)**



**Preferences by ethnicity**

*Weekday morning*  
15 White British, 1 South Asian

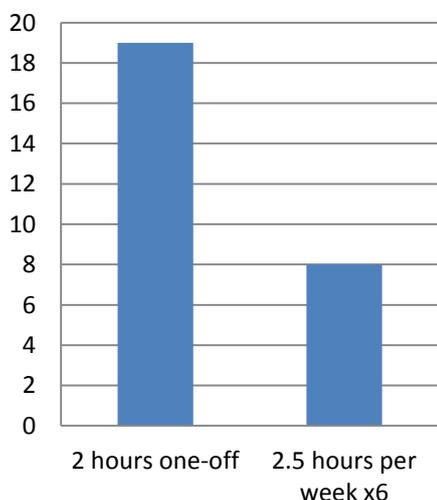
*Weekday afternoon*  
8 White British, 3 South Asian

*Early evening*  
4 White British, 0 South Asian

*Saturday*  
6 White British, 4 South Asian

*Sunday*  
3 White British, 1 South Asian

**Q5c) How much time could you spend to learn more? (tick one only)**



**Preferences by ethnicity**

*2 hours one-off:*  
13 White British, 6 South Asian

*2.5 hours per week x6*  
7 White British, 1 South Asian (in South Asian language)

**DISCUSSION**

60% of patients asked want to learn more about their diabetes. The proportion of the South Asian patients wanting to learn more was greater than the proportion of White British patients. The main reason for not wanting to learn more was that people felt they knew enough already. We did not explore current knowledge levels but, from talking to patients, knowledge seemed variable. The majority were happy to join a group session. GP practices and community centres were the most popular locations across both South Asian and White British patients. Only White British patient expressed interest in other locations. Weekday mornings were the most popular times for White British patients, with some interest in all other options. South Asian patients’ preferred weekday afternoons and Saturday mornings at 11.00. There was a preference for a one-off short course over a 6 week programme, particularly in the South Asian population.

It is acknowledged that this small patient sample is not necessarily representative of the local population, so the data needs to be triangulated with other data.

**NEXT STEPS**

Consider these results within the wider Patient and Public Engagement report, which will provide recommendations for improving access to structured education.

Louise Nash 13 July 2018

## 10. Emerging Themes – All Sources

### Barriers to Structured Education

- 6 sessions too much for some
- Potential participants think they know enough
- No flex in X-PERT to meet local community needs
- Thought of being at school
- No out of hours provision
- Poor HCP engagement with / enthusiasm for SE

### Barriers specific to the South Asian population

- Some do not speak English
- Transport
- Beliefs about how the body works
- HCPs often don't refer
- Prayer times
- Current provision not culturally appropriate
- Poor literacy

### Enablers to Structured Education

- Enthusiasm of HCP to attend
- Use of lay educators
- Re-offering
- Permission to bring partner
- Out of hours provision
- Choice of locations

### Enablers specific to the South Asian population

- Culturally appropriate content and activity
- Phone reminders before sessions
- Bilingual / bicultural educators
- Linking in with established groups
- South Asian recipes and pictures
- Visual aids

### Appropriate language

- "Course" rather than "SE"
- "Diabetes Made Easy" acceptable in English and Urdu/Punjabi
- Deliver course in Urdu and Punjabi

### How people want to learn

- Choice of locations – GP practices and community
- Choice of timings
- Need a shorter alternative to X-PERT

### How people want to learn: additional themes from South Asian population

- Desire for sessions with established groups
- Separate gender groups
- Avoid prayer times
- Make it a social event with refreshments

### What people want to learn – specific to South Asian population

- Foods to eat and avoid
- Hypo awareness
- Exercise with limited mobility
- Blood test results
- Staying health while abroad (men)
- Symptoms of diabetes
- Ramadan: what to eat and who should fast
- How to reward success
- Tests during sessions (men)
- Tobacco use
- Diabetes progression and signs of progression
- Diabetes prevention (for families)
- Healthy cooking methods
- Exercise recommendations

## 11.Recommendations and Next Steps

### Recommendations: development of new structured education provision

1. Develop a short course in addition to X-PERT with choice of locations and times, including out of hours provision
2. When developing courses, consider needs of attendees who do not need to lose weight
3. Develop and pilot courses tailored to South Asian population with content including:
  - use of ethnic foods
  - advice regarding fasting
  - simplified content with high visual element
  - South Asian language materials
  - consider practical ideas such as bringing in chapatis and weighing out rice
  - consider how to incorporate ideas from focus groups (Sections 7 and 8 – Conclusions and Recommendations)
  - social element with refreshments (fruit, tea/coffee)
  - appropriate timings and locations
4. Recruit bilingual / bicultural Language Support Worker(s) to support delivery in Urdu/Punjabi
5. Personalise recruitment methods for South Asian courses; consider asking GP practices to send appointment letters as an alternative to traditional referral route
6. Link with existing South Asian groups
7. Run South Asian courses in familiar environments
8. Provide single gender groups for South Asian courses

### Recommendations: strategies for improving uptake

9. Develop programme to better engage healthcare professionals with courses
10. Use the term “course” in place of “structured education”
11. Visit individual GP practices and share tools aiming to improve referrals to and uptake of courses including:
  - pathway with “referral to a course” at start of pathway
  - patient video
  - demonstration of elements of courses
  - guidance on recognising cues and triggers
  - streamlined referrals process
12. Develop strategy to recruit and use lay educators to support delivery of courses
13. Encourage attendance of family members
14. Develop a process for offering reminders to patients who have not attended a course

### Next steps for Structured Education team

- These recommendations have already been factored into the team’s plans when designing and delivering courses.
- Gather feedback from course participants in order to enable continued improvement.