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NHS Newcastle North & East and NHS Newcastle West Clinical Commissioning Groups

Diabetes Education: Patients’ Experiences of Current Courses and Views of Proposed Courses in Newcastle

September 2014

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Executive Summary

1.0 Introduction

NHS Newcastle North and East Clinical Commissioning Group (CCG) and NHS Newcastle West CCG are carrying out a review of type 2 diabetes education being provided to newly diagnosed patients.

The overall aim of this project was to test and explore type 2 diabetes patients' views on a draft service specification for structured diabetes education, to inform the final specification and future service provision for diabetes.

The key objectives of the project were to:

- Gauge awareness and uptake of current diabetes education courses
- Explore experiences of current education courses
- Identify any barriers to patients attending the current education courses
- Gauge levels of self-management amongst patients and any required support
- Discuss proposed education courses with patients and identify their preference and expectations of that course
- Explore patients preferences around location, timing and composition of courses
- Identify any barriers to the uptake of courses and suggestions for encouraging uptake
- Identify any other ways to receive education around diabetes

The project sought to engage with type 2 diabetes patients who had:

- Been newly diagnosed within the last 12 months
- Established diabetes with a diagnosis between one and five years ago

Via face-to-face interviews or online questionnaires and focus groups 94 people gave their views:

- Involve North East spoke to 84 people (see Appendix 4 for details)
- HAREF spoke to six people from black and minority ethnic communities (see Appendix 5 for details)
- Deaflink spoke to four people who were D/deaf (Deaf with a capital 'D' refers to those who identify with the Deaf community and culture and deaf with a lower case 'd', to those who are deaf and do not identify with the Deaf community) and others with sensory issues such as deafblind, Hard of Hearing and visual impairments

HAREF had a positive response to their recruitment drive with over sixty people interested in taking part. However, as the criterion for the work was those who had been more recently diagnosed, only six were eligible and took part in the engagement. The experience of one person who did not eventually take part in the research is worth noting however as it illustrates communication issues with people who have English as a second language around diagnosis of a condition.

This person from the Czech Republic was identified as having diabetes by their GP practice and invited by letter to take part in an interview. HAREF arranged language support for a telephone interview but at the beginning of the interview the person said that they did not think they had diabetes. This confusion illustrates the complexity of providing primary care support in the area of diagnosis of long term conditions, in which a lot of explanation and discussion is needed. Medical groups have highlighted the practical issue of managing appointments to meet need, in terms of the time required in interpreter supported consultations to ensure people have understood the information from health professionals.

Deaflink expected to engage with a low number of people due to the fact that D/deaf people are more likely to have undiagnosed diabetes (‘Sick of It – Report into the health of deaf people’, Signhealth, 2014). Sixteen people actually came forward to take part in the research but only four had been diagnosed within the last five years.

2.0 Current and proposed services

Currently, newly diagnosed patients living in the city are able to access two main services:

1. Diabetes Education and Self-Management for Ongoing and Newly Diagnosed course (DESMOND)

Patients are invited to attend DESMOND and this consists of two three-hour sessions, one week apart which take place at the Diabetes Centre, located at the Campus for Ageing and Vitality on Westgate Road. Up to 10 patients can attend (and can bring someone with them). The sessions are led by health professionals who are trained to ensure that patients are provided with up-to-date, evidence-based information. The course helps to educate patients about the type of diabetes they have, and provides practical advice on self-management of their condition. The course is not available for patients who require an interpreter or who are housebound.

2. Living well, taking control (LWTC)

This course is a pilot and has been operating for the last nine months, provided by HealthWORKS Newcastle. Again, newly diagnosed patients are referred to the course by their GP. It aims to help patients improve their lives and manage the condition and reduce longer term complications linked to diabetes. It consists of a set of six two hour group sessions which cover eating well, feeling good, stress and relaxation and reaching and maintaining the right weight. In addition, one-to-one support from a qualified health buddy is provided where attendees discuss their health and how to improve it. It is held at three community venues across the city at a variety of times, including morning afternoon, evening and weekends and participants may also bring along a carer, family member or friend.

The CCGs have drafted options for a new service specification for diabetes education which the engagement will help inform. The following three options have been developed although it should be noted that the final diabetes education service may include elements of all of them dependent on the outcome of the engagement:

- Education Option 1
    - This course would continue as described in DESMOND above

- Education Option 2
    - The course would take place in a community setting (e.g. a community centre)
    - Patients would attend more sessions than DESMOND which would be shorter in length, for example, six sessions of 2 to 2.5 hours. Sessions would be available during the day, on evenings or on weekends
    - It would be led by a healthcare professional trained to deliver education and there could also be trained community workers to support people further
    - This would be available in groups of 10-12 (plus family/carers) for English speaking groups and black and minority ethnic groups where they speak a language which is spoken by more than 3% of Newcastle’s population
    - For members of the black and minority ethnic community where their language is spoken by less than 3% of the population, there is an option for group education if enough people are available or they would have individual 1:1 sessions
    - For those who are housebound, who are care home residents or who have learning disabilities, non-group options would be available with a method more appropriate to their needs
- Education Option 3
    - This would be a computer-based course for those who have little time or would prefer not to attend classes
    - It would offer a shorter, briefer course with less information
    - It could be available in other languages if developed

3.0 Findings

3.1 Diagnosis and initial information

Of the 94 patients who took part in the research, 44.7% (42) had been diagnosed within the last year and 55.3% (52) had had their diagnosis for between one and five years. The majority of people had no symptoms of the condition and were unaware that they had the condition as it was either discovered after a routine blood test, they had presented at their GP with an unrelated illness or it was picked up during treatment for another condition they had.

> “I just had my regular yearly check-up and it showed up in my blood tests. It's just over 6.0 but to be honest I've never felt better!”

Four-fifths of people (76, 80.9%) received some information at their initial diagnosis about next steps, diet and weight loss, either in the form of written or verbal information. Thirteen people (13.8%) did not find the information useful and this was mainly due to the inaccessibility of it. Three HAREF participants found it difficult to access because of their level of English skill. One person who was blind was given a leaflet and another who was D/deaf found the language difficult to understand. The majority of those who did not receive information would have liked some (13 of 18, 72.2%) and information on diet, calories and recipes (taking into account the sorts of food that people cook across communities) was most frequently requested.

> “No, I was given pamphlets and I am blind”.

> “I would have liked diet stuff to begin with, example meals I could cook straight away”.

3.2 Experience of educational courses

Seventy-five (79.8%) had been offered the opportunity to attend either the DESMOND or LWTC educational course and two of those people had been offered both. Of this group 61 (81.3%) attended a course although two people chose not to attend the second DESMOND session.

3.2.1 DESMOND

3.2.1.1Attendees

Fifty-six people (82.4% of those offered) attended DESMOND. Referred by their GP or Practice Nurse they attended the Diabetes Centre, Brunton Park Health Centre or Molineux Street NHS Centre. Most people had expectations of the course and these were around being given general information about the condition or information about diet and foods to eat or cut out.

> “Help in knowing what would affect diabetes and to be explained exactly what diabetes is”.

Nearly two-thirds of people (24, 61.5%) felt that their expectations had been met and their experience was a positive one. They enjoyed meeting other people, sharing experiences, the course leaders and the format.

> “They gave very good information, presented in different ways and reinforced the message over the two sessions. The shared experience you get from the course was brilliant too. I think the social side is very important to go through the journey”.

Those 13 (34.2%) who felt expectations had not been met cited the skills and knowledge of course leaders, the content of the course being too much or too little information or not personalised, the intimidating large group size or the length of the session. One D/deaf participant was unhappy as they learnt that despite a support group being in operation in the city, there was no funding for D/deaf people to access it. Another three people commented that the sessions were too long, there were no refreshments and for one D/deaf person the fact that it had taken eight months to get onto the course due to interpreter bookings/fee issues. Also, for two HAREF participants there was a language barrier; they felt that it was very difficult to understand the information because the session was long and the language was complicated.

> “There were two nurses delivering the course, one was very knowledgeable and the other just kept apologising for not knowing much and being new which is ridiculous to admit. I dread to think how others in the room with no medical background would have felt. To be honest, I left after that first bit as I was appalled”.

> “I learnt there is a group that meet but no funding for the Deaf to access it. They have speakers which supplies information. I got more understanding of

> diabetes but by this time I had lost interest and couldn't care less what happens after realising the discrimination and lack of respect“.

Three-quarters of people (42, 75.0%) had been given ongoing support once the course had ended in the form of a manual/booklet to work through and urine blood glucose test kits. Three people said they were referred to HealthWORKS for lifestyle support and exercise. Eight people (19.0%) did not find the information useful due to the lack of detail within it. Seventeen participants (30.4%) requested other support, mainly around having follow-up session to check the progress of attendees within a year of the course. Six HAREF participants respondents requested follow-up sessions within their community-based groups to top-up messages about diet changes and where to go to exercise.

> “Well, I think it would be better to have a follow-up after the course to check you're doing okay and just so you don't feel you're forgotten”.

3.2.1.1Non-attendees

Those 12 people (17.6%) who were offered the course but did not attend described their reasons. Five were simply waiting for their start date, four people felt they knew enough about the condition and three people had been unwell. All but three said that they would consider attending in the future; two felt that they knew enough and one said that they were happy to just go to the dietician.

> “My brother and sister also both have type 2 diabetes and they told me everything”.

3.2.2 LWTC

Seven people (100.0% of those offered) attended the LWTC course. Referred by either their GP, Practice Nurse or a Health Trainer or finding out about it themselves, they attended the HealthWORKS building, Lemington Centre or Fenham Sure Start Centre. All felt their course expectations had been met and were very positive about it citing the interesting information and practical sessions in particular. They all received ongoing support in the form of a buddy who keeps in touch with them at regular intervals and received a booklet to take home and complete.

> “It’s a good approach with a lot of visual information…The group has been really useful for stress control and for recognising a range of symptoms that other people were describing, because I had been thinking I was going mad. It was so helpful to hear people talking about anxiety and I could think to myself ‘It’s not just me. It does happen to other people’. It was interesting listening to people from other cultures and hearing about different foods. There is a lot of home cooking in south Asian communities and so people don’t always know how to work out what’s in the food - there might not be any label. The healthy eating cooking sessions are very good because I’ve picked up things like using fromage frais and low fat yoghurt”.

3.2.3 Non-attendees

Nineteen people (20.2%) had not been offered the opportunity to attend an educational course and of these 11 (57.9%) had been diagnosed less than 12 months ago. Sixteen (84.2%) said they would consider attending in the future, one said they would not attend and two D/deaf participants did not answer.

3.3 Managing the condition

All but nine participants (9.6%) had made some sort of lifestyle change since being diagnosed, with the majority improving their diet and others exercising. Of the nine, five people said nothing would help them manage their condition, two requested more personalised information or exercises sympathetic to their disability or condition, one requested diet information, another recipes. Ten people (23.3%) requested something to help their family to support them with their condition mainly in the form of diet information.

> “I realised it’s not what I eat it’s how much when they showed me the plates on the course so I've cut down how much I eat”.
>
> “They find it difficult to help because they don't understand the eating pattern 'you can have a little' or 'I know diabetics who eat this' 'well I won’t have any then' and you feel guilty”.

3.4 Preferences of proposed changes to education courses

Option 1 - Structured DESMOND course
Option 2 - Within a community setting
Option 3 - Computer-based course

Participants were asked to consider which of the three proposed diabetes education course formats would suit them best if they were to consider attending a course in the future. The following options were chosen:

Preferred course	No. of responses*	% of participants
Option 1	34	36.2
Option 2	49	52.1
Option 3	9	9.6
No preference	1	1.1
None	2	2.1
Total	95	

*One participant could not choose between option 1 and option 2

3.4.1 The preferred option - Option 2

Option two was the preferred choice for the largest number of participants. The two main reasons for choosing this option were the preference for attending a course in a community setting so that they did not have to travel too far, were in a familiar setting and did not have the anxiety of going to hospital. They also preferred to have more sessions that were shorter in length, which would give them the opportunity to take the information in and formulate questions for the next session and be given the information in more manageable chunks. Eleven people (22.4%) liked the chance to meet people, including those from their local community and build up a rapport over a period of time and share ideas. Seven people liked the flexibility of the times and for a further seven having the course available in other languages was very important. All HAREF participants highlighted the value of bilingual workers as language can be a significant barrier to attending.

> “Bringing sessions out to places like here [venue of regular social group supported by the local authority] means it would get to people with a diagnosis of diabetes and their family members, as well as friends who might need to know things because there is diabetes within their families, or to be able to avoid developing diabetes.”
>
> “This will give you more time to digest the information and to get to know the group. The course I went on was rushed (DESMOND) - it would be better if it took longer with more time to digest the information and ask questions”.

Participants wanted to learn a variety of things from the course but in particular information about diet – what food they can and cannot eat and in what quantities - and seven people requested the same content as the DESMOND course, seven wanted information on how to manage their condition and seven, including six HAREF participants wanted information on how and where to exercise. One D/deaf participant felt strongly that the course should focus on imparting facts and not the sharing of attendees’ experiences as this resulted in the session they attended running over and their interpreters having to leave before all the information had been given out.

> “What foods to eat, the seriousness of diabetes and how to stop eating the foods that are bad for you”.
>
> “The same things that were covered on DESMOND but a bit more information on foods you could eat like a ratings system”.

Seventeen people (34.7%) however requested changes to this course, either by including aspects of the other courses or suggesting new things to include:

- Online information to support the course from a trusted source that they could refer back to x4
- Session times to mirror DESMOND x3
- Longer sessions
- 10 sessions, an hour in length
- Hospital setting x2
- Held at Deaflink
- Better management of attendees
- Smaller group size
- Follow-ups x2
- BSL interpreters available x2
- Information in Plain English and visual accompaniments e.g. Illustrating changes in the thickness of blood by showing water on its own and water with different concentrations of sugar in it, going through a straw.
- Include a cookery session

- Give the same information in different formats to reinforce the message

Two-thirds of people expected information to support them once the course was finished mostly in the form of leaflets, access to a helpline or manual.

3.4.2 Option 1

By far the most frequently mentioned reason (23, 69.7% of participants) for choosing Option 1 was the longer sessions over a shorter period which got it over and done with. Also seven people (20.6%) had been on the DESMOND course before and felt it worked well for them. Five people (14.7%) preferred a hospital location. They mostly wanted to learn about diet and the effects of the condition.

> "I'd prefer to get it over and done with in longer sessions".
>
> "For me, it would be better to get the time off work for just a couple of sessions than a whole course".
>
> "I'd want to learn more about the glycaemic index to find a list of good and bad foods".
>
> "Portion sizes, list of sugars and carbs in common foods, high risk foods, foods that have a green light, information on sugars in alcohol and alternatives".

Fifteen people however requested changes to this course, either by including aspects of the other courses or suggesting new things to include:

- Online information to support the course from a trusted source that they could refer back to x3
- More flexible times x3
- Community setting x3
- At home
- Include information about statins and diabetes
- More detailed information
- Clarification about high vs low carbohydrates diets
- Time to ask questions
- Remove the round robin introductions
- Larger room size
- Longer course
- More flexible times
- Different course leaders

Again the vast majority of people (97.1%) expected information to support them once the course was finished mostly in the form of leaflets.

3.4.3 Option 3

Nine people (9.6%) chose the computer-based option. The reasons given for choosing the computer option were that people could do it in their own time, they can do it at home and on their own, it is shorter than the other options and they can review the information and take time to understand it. They wanted to learn about diet mainly. One person requested a change to the course to include more tailored information. People requested a booklet, online information or access to a helpline and the chance to meet other diabetes patients.

> “The computer would be best for me - I can do it in my own time, I don't have to go anywhere, I don't have to sit in a room with lots of strangers, it’s just more convenient”.
>
> “When learning in a course via BSL, easy forget after the course and prefer on the computer so can read again and again repeat but want BSL on the computer to understand diabetes information better. I have a computer at home”.

3.5 Preferences of education courses generally

In addition to being asked their views around specific course formats, participants were also asked generally what their preferences were for a course location, leader, group type, time and duration.

Over half of people (53, 56.4%) requested a community location due mainly to convenience and feeling uncomfortable in a hospital setting and for HAREF participants, the reach of the course, as family members and friends and other people with the condition may be able to attend. One fifth of people (20.2%) had no preference of location. Everyone was happy to have sessions run by nurses or healthcare workers who were knowledgeable about the condition but one D/deaf person requested that they also had deaf awareness training and training materials to reflect that.

In terms of group types, 76.6% (72 people) had no preference. However, all six HAREF participants felt that having community-based groups was important so that family members and friends could also attend, four people asked for groups by age and three by similar blood glucose score, two people requested a group with other D/deaf people and one requested a single gender group. In terms of times and days, 28.7% of people (27) had no preference, the main times for others were daytime or mornings and weekdays. For the duration of the course and in contrast to the overall preference for Option 2, more people (41, 43.6%) requested longer but fewer sessions compared to 35 (37.2%) who wanted shorter but more sessions. Sixteen people (17.0%) had no preference. Twenty-two people (23.4%) suggested other ways to receive the information with six requesting a website to complement the course. Amongst other things emails, practice staff and leaflets were also mentioned.

3.6 Barriers to attending a course

Participants were asked whether anything would prevent them from attending a course. One third of people (33, 35.5%) felt that nothing would prevent them. For the remaining people the main reasons were the timing of the course, illness, accessibility issues or work commitments. In terms of accessibility issues, eight people (8.6%) highlighted not having the course provided in another language or having no spoken language support or an interpreter available, not being physically able to access the building due to a mobility chair and for the participant who was

DeafBlind they would need a minimum of double the usual time for communication with a manual interpreter so felt that attending a course was not an option for them.

> “I wouldn't go if they were only available in the evenings”.

> “I rely on a DeafBlind manual interpreter. I need a minimum of double the usual time for communication. I would not be able to join in group sessions”.

3.7 Encouraging people to attend a course

Fifty-eight people (61.7%) suggested ways to encourage people to attend a course in the future. The main suggestion, mentioned by 22.4% of people (13) was to stress the seriousness of the condition within the letter or during discussions with practice staff. Nine people (15.5%) felt that the benefits of the course needed more emphasis, six HAREF participants (10.3%) felt that proactively telling patients that there would be language support available would encourage black and minority ethnic communities to attend a course, five people suggested having the course endorsed by previous attendees and four suggested emphasising the fact that you can recover or get better.

> “Well, since I've been diagnosed I have to say I don't feel any different so for people like me I think they'd maybe need a shock to make them go on it - a leaflet explaining the things that could happen to you if you don't look after your diabetes”.

> “I work in a shop a couple of days per week and when I was diagnosed with diabetes I was devastated. I was absolutely terrified of going blind. People who come in the shop were asking how I was and when I told them, they would just say ‘oh, don't worry, it's just diabetes’. That's the problem - you need to get through to people how serious it is and make them realise it's not 'just' diabetes”.

3.8 Other comments

A number of people commented that they were looking forward to attending the DESMOND course, one participant requested a more personalised dietician session which took into account their other conditions and one requested a print out of their blood test results. Four people requested things around prevention that the health service could do; one wanted testing kits to be distributed to people to test themselves, one felt they should have been warned by their GP that they were at risk of developing the condition and two people who had been borderline for a length of time felt that they should have been offered a course around prevention.

> “I would like to have been offered the course sooner, i.e. before I actually got diabetes as I had three years of being borderline and I could have tried to do something about it through diet if I had had the information. - I had been following a Slimming World diet where you ate loads of carbs which I think didn't help!”

> “Why wasn't I given all this information when I was told I was borderline diabetic? This course would have been even more useful a year earlier when I was told I was borderline diabetic. Then I could maybe have

prevented becoming diabetic".

4.0 Recommendations

4.1 Key recommendation

4.1.1 Recommendation 1: Preferred option
In terms of participants' preference for an education course, 49 people (52.1%) stated that they would choose option 2 if they were to attend in the future compared to 34 people (36.2%) who would choose option 1 and nine people (9.6%) who would choose option 3.

It is recommended that:

- If only one course format can be offered to patients in the future, consider providing option 2. However it must be noted that in terms of option 3, the cohort of people we spoke to was older people; we did not speak to anyone 34 or under and nearly two-thirds were 65 and older. Therefore, this option may have been more preferable to a younger age group.

4.2 Diagnosis

4.2.1 Recommendation 2: Diagnosis information
Thirty-two people (34.0%) suggested information they would have liked to receive at their diagnosis to enable them to start making immediate changes to their lifestyle and five people had difficulties accessing the information.

It is recommended that:

- Patients receive some more detailed information they can take away from the consultation around diet so that they can start to make changes straightaway before seeing a dietician or going on a course. This should include the best foods to eat and cut out, how to understand food labelling and some example recipes taking into account the sorts of food that people cook across communities. This information should be appropriate to the patient taking into account their level of English and any disabilities they may have.

4.3 Education courses

4.3.1 Recommendation 3: Accessing the course
One D/deaf participant had to wait eight months to get onto the course due to interpreter booking/fee issues.

It is recommended that:

- The appointment system for booking onto a course is flexible enough to take into account people who may need extra support to attend, ensuring that there are no delays for anyone accessing the course.

4.3.2 Recommendation 4: Course accessibility
Several participants requested access to BSL interpreters, spoken language support and information provided in Plain English with visuals. One participant felt that the course leaders should also have deaf awareness training.

It is recommended that:

- Any course takes into account the accessibility needs of all patients to ensure that everyone can attend a diabetes course if they wish

4.3.3 Recommendation 5: Course management

One D/deaf participant felt strongly that the course should focus on imparting facts and not the sharing of attendees' experiences as this resulted in the session they attended running over and their interpreters having to leave before all the information had been given out.

It is recommended that:

- Sessions are strictly managed in terms of timings to ensure that all attendees have the opportunity to gather all of the information on offer.

4.3.4 Recommendation 6: Course location

Participants were asked generally what their preferences would be for a course location 53 people (56.4%) requested a community location compared to 18 people (20.5%) who would prefer a hospital based course and 19 people (21.6%) had no preference.

It is recommended that:

- Courses be offered at community locations.

4.3.5 Recommendation 7: Course times

Participants were asked generally what their preferences would be for course times. Twenty-five people (26.6%) would be happy to attend a course during the daytime, 14 (14.9%) would prefer mornings, 11 (11.7%) afternoons and weekdays were requested by eight people (8.5%). In addition, when asked about barriers to attending a course, the timing of it was an issue for 10 people (10.6%) and others said it would depend on other personal or work commitments.

It is recommended that:

- Patients are offered a selection of course times, either during the mornings, afternoons or evenings to enable them to attend a course.

4.3.6 Recommendation 8: Course duration

Participants were asked generally what their preferences would be for the course duration. In contrast to the preference for Option 2, people would prefer longer but fewer sessions. Forty-one people (43.6%) requested this option compared to 35 (37.2%) who would prefer shorter sessions over a longer period although it must be noted that the difference in numbers is marginal.

It is recommended that:

- Consideration is given to the optimum duration of the course and length of session times. It is suggested however that session times should possibly not be as long as three hours or if this length of time is chosen, ensure that there is a break and refreshments available for attendees.

4.3.7 Recommendation 9: Course content

Participants were asked what they would like to learn from a diabetes education course. Numerous suggestions were made but those mentioned by at least ten percent of people were mainly around diet (40 people, 50.0%) followed by how to manage the condition (10 people, 12.5%) the same information as was given on the DESMOND course (nine people, 11.3%) and how and where to exercise (11.3%).

It is recommended that:

- The course content is examined and if deemed necessary, some additional information be provided around diet, management of the condition and appropriate exercises to do and where to go to do them. In particular, what foods they can and cannot eat and in what quantities, food labelling and the glycaemic index, again taking into account the sorts of food that people cook across communities.

4.3.8 Recommendation 10: Support once the course had ended

Thirty-six people (38.3%) requested leaflets, 12 people (13.8%) requested a manual, 11 people (11.7%) requested access to a telephone helpline and 11 people (11.7%) requested follow-up sessions once the course had ended. In addition, 11 participants who had attended the DESMOND course requested additional support or information once the course was over in the form of follow-up sessions to check progress of attendees and top-up messages about diet changes and where to go to exercise. Six HAREF participants respondents requested that this follow-up take place within their community-based groups (where other family, friends or community members could attend) and within a year of attending the course. In contrast, none of the seven people who attended the LWTC which has ongoing support in the form of a buddy, requested any additional support.

One D/deaf participant asked about the availability of support groups and although there is one operating in the city, they were informed that there was no funding to help them access the group. Furthermore, when asked what changes participants would like to the course they had chosen, a further two people requested follow-ups and nine people requested online information to support the course from a trusted source that they could refer back to.

It is recommended that:

- Patients receive some form of support once the course is over but in particular consider providing:
    - Leaflets
    - A manual that they can work through or refer back to
    - A helpline
    - Some form of follow-up session provided about a year after attendees have completed the course to see how they are progressing and offer refresher information in a community setting.
    - The buddy system used by LWTC.
    - Support groups for attendees to access after the course or if this is not possible, ensure attendees are given up-to-date information about how to access groups in the community.
    - An online website to accompany the course and act as a reference point.

  If these suggestions are not viable ensure that attendees have, at the very least, a contact number to call in case they have any queries about the information they have learned on the course.

- Consideration is given to how those requiring extra support to attend a group are able to attend community-based support groups.

4.4 Encouraging people to attend the course

4.4.1 Recommendation 11: Methods of encouragement

Fifty-eight participants (61.7%) made suggestions about what might encourage people to attend an education course. Thirteen people (22.4%) felt that the seriousness of the condition needed more emphasis, nine people (15.5%) felt that the benefits of the course needed to be more clearly advertised and six HAREF participants (10.3%) felt that proactively informing people that language support will be available would also encourage people to attend.

It is recommended that:

- Any information about education courses emphasises the seriousness of the condition and in particular how not managing diabetes can lead to deterioration of eye sight and feet problems. The benefits of the course should also be emphasised more clearly as should the availability of language support.

4.5 Prevention

4.5.1 Recommendation 12: Preventing the disease

Four people (4.3%) made suggestions around preventing the disease – distributing testing kits to patients, informing patients in advance that they made be at risk of diabetes and offering borderline patients the opportunity to attend a course around prevention.

It is recommended that:

- Although only four people had issues around prevention it is felt that any actions around this would have a noticeable impact on people developing diabetes in the city. Therefore, it is recommended that patients at risk of developing diabetes are offered the opportunity to attend a preventative course. If a course is not a feasible option, these patients should be given information about how to prevent themselves developing the condition.

Section 1 – Introduction

1.0 Introduction

1.1 NHS Newcastle West and Newcastle North and East Involvement Forum

1.1.1 Involve North East

Involve North East is an independent charity working across Newcastle and the North East. We are experts in innovative and practical involvement, working with patients, communities and harder to reach groups to gain the insight needed to design the best, most responsive and cost-effective health and social care services.

1.1.2 Health and Race Equality Forum (HAREF)

HAREF is a network focused on reducing inequalities. The network keeps the voices of people across black and minority ethnic communities heard in settings where decisions are made about health service developments. Positive relationships, consistency and quality are at the heart of the work of the Health and Race Equality Forum.

1.1.3 Deaflink

Deaflink is an open, inclusive and supportive organisation working to empower and improve the quality of life of D/deaf, hard-of-hearing and deafblind people in Newcastle. We aim to improve access to employment, education, health, leisure and social opportunities and to raise awareness of the needs of these excluded groups to organisations and agencies through training, support and advocacy.

1.2 Context

Diabetes is a condition where the body is unable to move sugar from the blood stream into the muscles and brain where it can be used. This becomes increasingly common with age but Type 2 diabetes is largely a result of eating quantities in excess of what is needed by the body.

The excess sugar leads to people feeling unwell and also causes damage to the circulation, the heart, the kidneys, the eyes and the nervous system causing pain and disability. Diabetes reduces fertility, increases the likelihood of abnormal babies and death around the time of birth and increases risks to the mother.

Patients are more likely to develop Type 2 diabetes if they:

- are over 40 years old
- have a relative with the condition
- are of South Asian, African-Caribbean or Middle Eastern origin
- are overweight or obese

According to the National Diabetes Information Service as of 2012, diabetes prevalence rates in Newcastle were as follows:

Area	**Number***	**Prevalence**
NHS Newcastle North and East CCG	7,038	6.0%
NHS Newcastle West CCG	9,061	8.0%

*Figures are based on resident population

A diagnosis of Type 2 diabetes will, for the majority of patients, require some level of lifestyle change. Changing lifestyle by improving diet, increasing exercise and losing weight can not only can make patients feel better and reduce the risks of diabetes, but can sometimes cure or delay the onset of the condition.

1.2.1 Diabetes education

In order to support patients who have been newly diagnosed the National Institute of Clinical Excellence (NICE) recommend that people with diabetes and/or their family or carers, be offered education programmes to help them manage their condition and make the appropriate lifestyle changes.

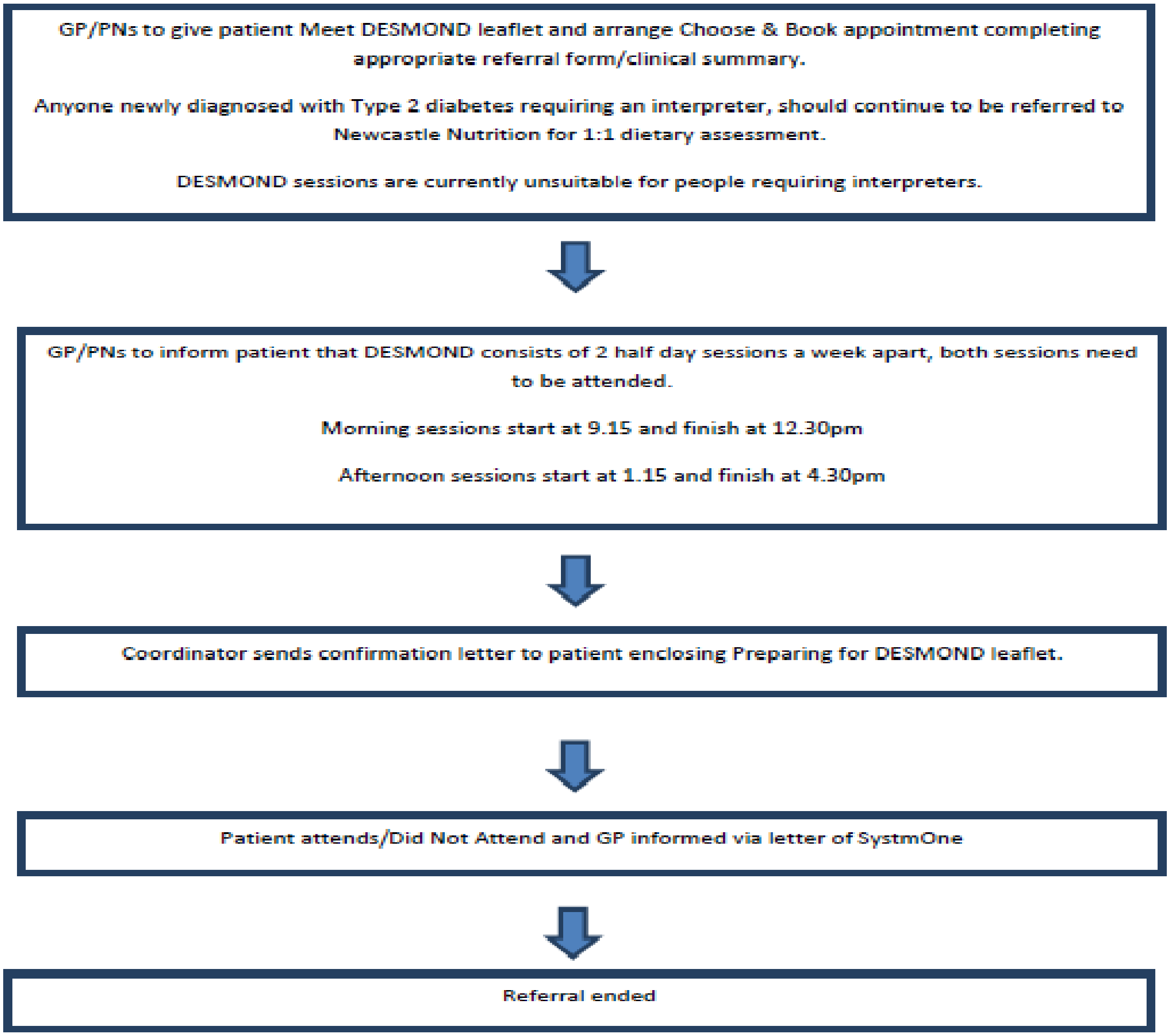
1.2.2 Current diabetes education in Newcastle

In Newcastle, diabetes education is seen as an essential part of treating the condition and is offered to the patient and their close family. Currently, newly diagnosed patients living in the city are able to access two main services:

1. Diabetes Education and Self-Management for Ongoing and Newly Diagnosed course (DESMOND)

Patients can attend education sessions provided by the Community Health service at Newcastle upon Tyne Hospitals NHS Foundation Trust as follows:

DESMOND Referral Pathway



GP/PNs to give patient Meet DESMOND leaflet and arrange Choose & Book appointment completing appropriate referral form/clinical summary.

Anyone newly diagnosed with Type 2 diabetes requiring an interpreter, should continue to be referred to Newcastle Nutrition for 1:1 dietary assessment.

DESMOND sessions are currently unsuitable for people requiring interpreters.

GP/PNs to inform patient that DESMOND consists of 2 half day sessions a week apart, both sessions need to be attended.

Morning sessions start at 9.15 and finish at 12.30pm

Afternoon sessions start at 1.15 and finish at 4.30pm

Coordinator sends confirmation letter to patient enclosing Preparing for DESMOND leaflet.

Patient attends/Did Not Attend and GP informed via letter of SystmOne

Referral ended

As illustrated above, patients are invited to attend DESMOND and this consists of two three-hour sessions, one week apart which take place at the Diabetes Centre, located at the Campus for Ageing and Vitality on Westgate Road. Up to 10 patients can attend (and can bring someone with them). The sessions are led by health professionals who are trained to ensure that patients are provided with up-to-date, evidence-based information. The course helps to educate patients about the type of diabetes they have, and provides practical advice on self-management of their condition and in particular covers:

- What diabetes is
- How to make healthy food choices
- How to increase exercise
- What are the risks with diabetes and how these risks are monitored and modified

- What to expect from the Health Service and influence this
- How to be able to participate in making decisions about their care and keep their own personal record and discuss this with their health care workers

The course is not available for patients who require an interpreter or who are housebound.

2. Living well, taking control (LWTC)

This course is a pilot and has been operating for the last nine months, provided by HealthWORKS Newcastle. Again, newly diagnosed patients are referred to the course by their GP. It aims to help patients improve their lives and manage the condition and reduce longer term complications linked to diabetes. It consists of a set of six two hour group sessions which cover eating well, feeling good, stress and relaxation and reaching and maintaining the right weight. In addition, one-to-one support from a qualified health buddy is provided where attendees discuss their health and how to improve it. It is held at three community venues across the city at a variety of times, including morning afternoon, evening and weekends and participants may also bring along a carer, family member or friend.

The hospital also offers a dietician led group for English speakers and an individual diet session for people requiring interpreters - as this latter group is currently excluded from the Desmond course, the dietician covers some elements of the structured education programme.

1.2.3 Proposed diabetes education in Newcastle

NHS Newcastle North & East Clinical Commissioning Group (CCG) and NHS Newcastle West CCG have drafted options for a new service specification for diabetes education. The following three options have been developed although it should be noted that the final diabetes education service may include elements of all of them, dependent on the outcome of the engagement with patients (as outlined in section 1.3 below):

- Education Option 1
    - This course would continue as described in DESMOND above

- Education Option 2
    - The course would take place in a community setting (e.g. a community centre)
    - Patients would attend more sessions than DESMOND which would be shorter in length, for example, six sessions of 2 to 2.5 hours. Sessions would be available during the day, on evenings or on weekends
    - It would be led by a healthcare professional trained to deliver education and there could also be trained community workers to support people further

    - This would be available in groups of 10-12 (plus family/carers) for English speaking groups and black and minority ethnic groups where they speak a language which is spoken by more than 3% of Newcastle's population
    - For members of the black and minority ethnic community where their language is spoken by less than 3% of the population, there is an option for group education if enough people are available or they would have individual 1:1 sessions
    - For those who are housebound, who are care home residents or who have learning disabilities, non-group options would be available with a method more appropriate to their needs

- Education Option 3
    - This would be a computer-based course for those who have little time or would prefer not to attend classes
    - It would offer a shorter, briefer course with less information
    - It could be available in other languages if developed

1.3 The project

1.3.1 Aim

The overall aim of this project was to test and explore patients' views on a draft service specification for structured diabetes education, to inform the final specification and future service provision for diabetes.

1.3.2 Objectives

The key objectives of the project were to:

- Gauge awareness and uptake of current diabetes education courses
- Explore experiences of current education courses
- Identify any barriers to patients attending the current education courses
- Gauge levels of self-management amongst patients and any required support
- Discuss proposed education courses with patients and identify their preference and expectations of that course
- Explore patients preferences around location, timing and composition of courses
- Identify any barriers to the uptake of courses and suggestions for encouraging uptake
- Identify any other ways to receive education around diabetes

Section 2 - Methodology

2.0 Methodology

In order to meet the objectives of the project, a number of distinct and complementary qualitative techniques were used. A qualitative methodological approach was deemed to be the most appropriate as it is concerned with gaining a depth of understanding of how people feel, their beliefs, reasoning and motivations and therefore fitted with the objectives of the project.

2.1 One-to-one interviews

Eighty-five one-to-one interviews took place with patients either by telephone or face-to-face. Interviews allowed us to explore issues arising from the questions we ask, and to prompt interviewees to elicit richer and more detailed responses than is usually yielded by self-administered questionnaires.

2.2 Self-administered questionnaires

In order to enable as many people as possible to give their views, within a short timeframe, an online questionnaire was also developed and used by Deaflink which was accessible to those who are Hard of Hearing. The questions were the same as those used in the interviews to enable consistent data collection and analysis.

See Appendix 1 for questions.

2.3 Focus groups

Three focus or group discussions also took place which included six relevant patients. Focus groups take place within a group setting with members sharing a common interest which enables them to feel comfortable and able to give their views freely. In addition, interaction within the group may also produce other data, when for example a memory is triggered by someone else’s comments. The focus group schedule covered the same topic areas as the questions so as to allow the same data to be collected and analysed.

See Appendix 2 for focus group schedule.

2.4 Participants

The project sought to engage with Type 2 diabetes patients who had:

- Been newly diagnosed within the last 12 months
- Established diabetes with a diagnosis between one and five years ago

- In order to recruit and engage participants the three organisations used the following methods:

- Involve North East recruited and engaged patients via:
    - All GP practices in the city who were asked to identify 30 patients – 15 newly diagnosed patients and 15 patients with established diabetes. They were sent a letter asking them to take part in the research
    - The 'Living Well, Taking Control' diabetes education course run by Newcastle HealthWORKS
    - Next Steps exercise on referral class run by Newcastle HealthWORKS
    - The Newcastle branch of Diabetes UK
    - Involve North East's and Healthwatch Newcastle's e-news recipients

- HAREF recruited and engaged patients who were from minority ethnic communities via:
    - their contacts and networks

- Deaflink recruited and engaged patients who were D/deaf patients (Deaf with a capital 'D' refers to those who identify with the Deaf community and culture and deaf with a lower case 'd', to those who are deaf and do not identify with the Deaf community) and others with sensory issues such as deafblind, Hard of Hearing and visual impairments via:
    - their contacts and networks
    - an online questionnaire

Overall we engaged with 94 people. For a full participant profile, see Appendix 3.

- Involve North East spoke to 84 people (see Appendix 4 for details)
- HAREF spoke to six people (see Appendix 5 and 8 for details)
- Deaflink spoke to four people (see Appendix 6 and 7 for details)

HAREF had a positive response to their recruitment drive with over sixty people interested in taking part. However, as the criterion for the work was those who had been more recently diagnosed, only six were eligible and took part in the engagement. The experience of one person who did not eventually take part in the research is worth noting however as it illustrates communication issues with people who have English as a second language around diagnosis of a condition.

This person from the Czech Republic was identified as having diabetes by their GP practice and invited by letter to take part in an interview. HAREF arranged language support for a telephone interview but at the beginning of the interview the person said that they did not think they had diabetes. This confusion illustrates the complexity of providing primary care support in the area of diagnosis of long term conditions, in which a lot of explanation and discussion is needed. Medical groups have highlighted the practical issue of managing appointments to meet need, in terms of the time required in interpreter supported consultations to ensure people have understood the information from health professionals.

Deaflink expected to engage with a low number of people due to the fact that D/deaf people are more likely to have undiagnosed diabetes (‘Sick of It – Report into the health of deaf people’, Signhealth, 2014). Sixteen people actually came forward to take part in the research but only four had been diagnosed within the last five years.

Section 3 – Findings

3.0 Findings

This section provides a summary of the findings of Involve North East's, HAREF's and Deaflink's research with ninety-four diabetes patients:

- Forty-two patients (44.7%) had had their diagnosis for less than one year
- Fifty-two patients (55.3%) had had their diagnosis for between one and five years

For a full participant profile, see Appendix 3. For a copy of HAREF's findings see Appendix 7, for a copy of Deaflink's findings Appendix 8.

3.1 Diagnosis

Patients were initially asked how their diagnosis came about.

Diagnosis	**No. of participants**	**% of participants**
Annual health check	40	42.6
Presenting at GP with an illness	22	23.4
Through another condition	5	5.3
Work health check	26	27.7
Other	1	1.1
Total	94	100

Type 2 Diabetes is often asymptomatic in its early stages and as the table above shows, for the majority of people their diagnosis followed a routine blood test conducted during an annual health check. One patient who found out this way was unhappy that they were not actually told directly that they had the condition until they asked the question outright.

> "I had my annual MOT at the GP's in the afternoon and got a phone call from Northern Doctors at 8.15pm that night telling me to come immediately to the drop-in at Rake Lane as I could go into a coma at any time! But nobody actually mentioned the word 'diabetes' until about a week and a half after - I got a letter from the surgery asking me to go for a diabetes review. When I saw the doctor at my review, I directly asked the doctor 'does that mean I've got diabetes?' and they said 'yes'".
>
> "I just had my regular yearly check-up and it showed up in my blood tests. It's just over 6.0 but to be honest I've never felt better!"
>
> "I had a health MOT and they found it in my blood test. I was thirsty a lot but didn't think much of it".

About one third of people did present at their GP practice when feeling ill although only half of these had symptoms associated with the disease.

> "I went to the doctor as I was exhausted. I had a blood test and they found out I was anaemic and diabetic".
>
> "I was having problems with my eyes."
>
> "I went with some symptoms - thirsty, not feeling full when eating, lethargic".

Others presented as follows:

> "I was getting chronic heart burn. My GP sent me to the Freeman [Hospital] and I came back with type 2 diabetes".
>
> "I went to the doctors with some symptoms of getting out of breath when I was walking; they did a blood test and found it".
>
> "I was having some stomach problems and had a blood test which showed it up".

Most of the remaining patients had found out through treatment for another condition that they already had.

> "I had a heart bypass 10 years ago and I had to go for my regular check-up, they take my blood and that's how it was found".
>
> "I got some symptoms from tablets I was taking for gout and they did some blood tests which came back abnormal and I was then diagnosed".
>
> "I had a stroke a few years ago and it was picked up during some routine blood tests for that. I had and still have no symptoms".

3.2 Initial information

Patients were also asked whether at their diagnosis, they were given any information about diabetes, what it was and whether they were satisfied with the information they received.

Four-fifths of people (80.9%) were given some form of information about their diagnosis. This was either in the form of leaflets or verbal information from the nurse or their GP which covered what happens next, diet and weight loss information. Eight people specifically mentioned that the DESMOND course had been discussed with them.

Thirteen people (13.8%) felt that the information they were given was not useful for the following reasons:

Reason	No. of participants
Inaccessible information	5
Information was too brief	3
Too much information	1
Confusion over next steps	1
No opportunity to question information	1
No reason given	2

Five people felt that the information was inaccessible to them. For three HAREF participants they found it difficult to access it because of their level of English skill. One person who was blind and another who was D/deaf also felt that the information was not appropriate for them.

> “No, I was given pamphlets and I am blind”.
>
> “Some words, hard to understand and I have to ask what they meant”.

Not being able to ask questions of the information was also an issue for one D/deaf participant. They felt that the leaflet was okay but it is “hard to ask about the information and what words means as nurse not available all the time”. This led to them searching online and contacting Diabetes UK to get some answers around diet. They were told that the organisation does not work with D/deaf people and were referred to Action on Hearing Loss who subsequently said they “don't do diabetes!”

Of the 18 people (19.1%) who did not receive any information 13 (72.2%) felt that it would have helped them and all patients were asked what other information they would have liked. Thirty-two patients (34.0%) suggested that the following information should be provided at diagnosis:

Type of information	No. of responses*
Diet/calories/recipes	17
Effects of diabetes	6
Accessible information	5
More information generally	3
Weight loss	2
Management of condition	2
Why they had developed it	2
Exercise	2
Practical information e.g. classes to go to	1
How to take care of feet	1
How to avoid infection	1

*Participants could give more than one response

Most people requested more information about diet to enable them to start making changes to their lifestyle immediately. They requested example recipes (taking into account the sorts of food that people cook across communities) or information about food labelling so that they could make informed choices about the food they were eating from the outset.

> “I would have liked more diet information - calories in food and how to understand nutrition on food packets”.
>
> “I would have liked diet stuff to begin with example meals I could cook straight away”.
>
> “I would have liked diet information sooner”.
>
> “What to eat and how to put that information into practice with the food we cook”.

How diabetes may affect them was also requested by six people.

> “Well it wasn't impressed on me the importance of having diabetes and because of that I didn't change my diet straightaway so some more information like that would have been good”.
>
> “Watch diet, kidneys, exactly what diabetes is like, need warnings about eye health”.
>
> “How it affects people, signs to look for and how to prevent deterioration”.

Accessible information was also requested by a participant who was blind and one D/deaf person requested “simple information about food with pictures”. Information for three participants who do not have English as a first language was also requested.

In terms of exercise, one HAREF participant wanted information about where to go, including women-only spaces, to get into the habit of exercising”.

3.3 Experience of educational courses

Patients were also asked whether they had been offered the opportunity to attend any educational courses after their diagnosis. Eighty people (85.1%) said that they had been offered the opportunity although five of those were referring to the dietician group talk currently running as an interim course at the Diabetes Centre which has not been included in this analysis.

In total therefore, 75 people (79.8%) were offered courses although two people were offered both the DESMOND and Living Well, Taking Control course:

- 68 people (90.7%) were offered DESMOND
- 7 people (9.3%) were offered Living Well, Taking Control
- 2 people (2.7%) could not remember what the course they had been offered was called.

3.3.1 Course attendees

Of this group 61 (81.3%) attended the courses they had been offered although two people chose not to attend the second DESMOND session. Those who attended a course were asked about their experience.

3.3.2 DESMOND

3.3.2.1Attendees

Fifty-six people (82.4% of those offered) chose to attend the DESMOND course. The vast majority were referred through their GP surgery by either their GP or the Practice Nurse and received a letter inviting them to attend. One person said that the practice Receptionist referred them, another that the Dietician did so and a third said that their GP had given them a number to call themselves. One patient said that they found out about it themselves through regular attendance at the Diabetes Centre. One D/deaf patient highlighted particular problems they had in trying to access the course.

> "With great difficulty!!!! Problems over interpreter bookings/fees delayed my attendance. Once on the course everyone was referred to the course within six weeks whereby I finally attended eight months later".

They accessed the course at the following locations:

Reason	No. of participants
Diabetes Centre	27
Brunton Park Health Centre	16
Molineux Street NHS Centre	13

In terms of their expectations of the DESMOND course 17 people (30.4%) said that they had no expectations at all and one person said they knew exactly what to expect as they had been a District Nurse.

> "I didn't really have any".
>
> "Nothing - I'd never heard of it".
>
> "I wasn't sure what to expect, I got a letter which did tell me a little about the content".

The remaining 38 participants (67.9%) had the following expectations:

Expectation	**No. of responses***
To be given general information about diabetes	20
To be given information about their diet/foods to eat or cut out	12
To be given information about how to manage the condition	5
To meet other people with the condition	4
To get some advice	3
To understand why they had developed diabetes	3
To be given information about the effects of diabetes	1
To be given information as described in the diabetes leaflet	1
To be given lifestyle information	2
To be given more information	1
To be given information about the symptoms	1
To be given information on any peer support groups	1
That I was not going to like it	1

*Participants could give more than one response

As can be seen from the table above, most people wanted general information about diabetes.

> "Help in knowing what would affect diabetes and to be explained exactly what diabetes is".
>
> "General information about how to look after it and the implications of having it".
>
> "I hoped it would make my knowledge of diabetes clearer".

Others wanted information about diet and the best foods to eat to help control their diabetes.

> "I thought I would learn about diet, what to be cautious of such as sugar and salt".
>
> "Diet - what we could and couldn't eat".
>
> "I expected to be told what foods you could eat and the values of them, like the ratings red, orange and green".

How to manage their condition and having the opportunity to meet other people with diabetes was also an expectation for some.

> "To learn about diabetes and why I got it and how to control it".
>
> "Just how to manage it".
>
> "I tried not to have too many, for me it was more about meeting other people with type 2 diabetes".

> “I wanted to hear other people's experiences and how to manage my condition”.

Of the 38 people (67.9%) who had expectations of the course, 24 (61.5%) felt that these expectations had been met, 13 (34.2%) felt that they had not and one person could not remember. In addition to getting the information that they expected, attendees particularly enjoyed meeting other people with diabetes and sharing experiences and ideas. Several people commented positively on the course leaders and the format.

> “They gave very good information, presented in different ways and reinforced the message over the two sessions. The shared experience you get from the course was brilliant too. I think the social side is very important to go through the journey”.

> “It was good - mainly because of the chance to meet others with the same condition and the diet information was really good as I was quite overweight”.

> “The people were really nice. The people delivering the course were great and they had good resources that we could look at. There were lots of opportunities to discuss things and ask questions”.

> “I think they gauged the level of information well and it's sensible to have two segments. I was also able to meet other people and it’s good to know you’re not alone”.

Those 13 (34.2%) who said that their expectations had not been met cited the skills and knowledge of course leaders as an issue. Their knowledge and ability to control a group were questioned.

> “There were two nurses delivering the course, one was very knowledgeable and the other just kept apologising for not knowing much and being new which is ridiculous to admit. I dread to think how others in the room with no medical background would have felt. To be honest, I left after that first bit as I was appalled”.

> “One of the nurses wasn't familiar with the material and didn't have the knowledge and I had no confidence in her at all. She was also very overweight which is not a good example for diabetic people”.

> “She didn't control the meeting and people just talked and went on and on”.

The course content was also questioned, two people felt that there was too much information, whilst another felt that “it was aimed too low”, one person didn’t get the information they expected and another disagreed with some of the advice they gave around carbohydrates.

> “The people running it were lovely and they have to follow a set programme, but it was aimed too low as if we knew nothing. I felt like they were treating us like

> children. I also felt like there was a presumption that if you are diabetic then you're overweight which is a bit insulting because I'm not”.

> “Too many people firing questions for their own agenda, too much info all at once. Also had to take unpaid leave. Didn't go back; it wasn’t worthwhile for me”.

In terms of the format of the course, two people disliked the fact that it was in a large group which they found intimidating whilst another too felt it was simply too long a period to sit and take information in.

> “I'm an ex-nurse and I'm used to sitting listening to lectures and talks but it was the worst presentation I've ever seen. For starters the first section was 1.5 hours long without a break which was just too long”.

> “I didn't get my questions answered. There was too many people attending. I was frightened to ask things. I couldn't get a word in as it was too busy”.

> “One can only take in so much new information and especially when elderly [60+ years]”.

A further three people requested more “tailored information”.

> “I am not overweight and I have a good diet and I am vegetarian”.

> “They aim the course at the middle masses not people on the periphery. Most people were elderly, fat women”.

One participant was given the information they expected but was unhappy with what they learnt about the lack of support for D/deaf people.

> “Yes and No. I learnt there is a group that meet but no funding for the Deaf to access it. They have speakers which supplies information. I got more understanding of diabetes but by this time I had lost interest and couldn't care less what happens after realising the discrimination and lack of respect“.

Unrelated to expectations about the course, six people commented negatively about it. They cited the session length, the lack of refreshments and for one D/deaf person, the length of time it took to get onto the course compared to hearing people. Also, for two HAREF participants there was a language barrier; they felt that it was very difficult to understand the information because the session was long and the language was complicated.

> “The DESMOND course was awful. Three hours is too long to sit in one place and it was really hot”.

> “We needed snacks or tea after three hours but there were no refreshments provided”.

> “Anger at being left for so long to attend course compared to hearing”.

Patients were also asked whether they had been given any ongoing support once the course had ended and 42 (75.0%) had been. The majority of people recalled being given a booklet/manual to read with exercises to work through once the course had finished, it also included telephone numbers. Others said that they also received urine dip sticks to test their blood sugar levels. A further three people said that they were referred to HealthWORKS for ongoing support around lifestyle changes and using the gym.

> “Yes, I got a self-help booklet which had aims and places to record how you were getting on”.
>
> “I got a pack/file and exercises to write up which was really good and there were telephone numbers in there”.
>
> “Information pack and urine sticks to test blood sugar”.
>
> “I went along to the sport centre where I talked with someone about how to manage/lose weight”.

Eight people (19.0%) did not find the information and support useful; those who gave a reason cited the content of the booklet or the lack of incentive to use it once the course was over.

> “I got a booklet and it was too vague. It just kept saying it depends on the level of diabetes you have rather than personalising it”.
>
> “All I wanted to know was the percentage of sugar per day and I had to find all that out by myself”.
>
> “It was [useful] while you were doing the course and just after but then it just gets forgotten about”.

All attendees were asked whether there was any other support or information they would like to have received once the course was over. The following were mentioned by 17 people (30.4%):

Ongoing support/information	No. of participants
Follow-up sessions to check progress of attendees	11
Diet/foods	5
Reversing the condition	2
Access to peer support groups for D/deaf people	1
Website to support course including all course materials	1
Effects on eyesight	1
Tailored information for people with Crohns disease	1
How/why you develop diabetes	1
Blood glucose test packs instead of urine sticks	1
The link between diabetes and statins	1

Follow-up sessions were the most frequently mentioned with people requesting a follow-up with nurses within a year of the course. Black and minority ethnic respondents engaged by HAREF requested sessions with their community-based groups, to top-up messages about how to make changes in diet and where to go to exercise.

> "A follow-up meeting as the diabetic nurses were very good".
>
> "Follow-up, for example, a year later to check how you're getting on".
>
> "Well, I think it would be better to have a follow-up after the course to check you're doing okay and just so you don't feel you're forgotten".
>
> "A list for shopping what and what not to buy - food I can eat [patient is vegetarian]".
>
> "The percentage of sugar in foods".
>
> "I would like the information to have focused on ways you could manage it successfully rather than focusing on the official line that it's incurable because people just think what's the point".
>
> "I have a medical every year and I didn't have diabetes, then when my dosage of statins was increased, I developed type 2 diabetes. When I went to DESMOND, we went round the group to introduce ourselves as an ice breaker and every other person in the group was also on statins".

3.3.2.2Non-attendees

As highlighted above, 56 of the 68 people (82.4%) offered the DESMOND course chose to attend. The remaining 12 (17.6%) were asked why they had not taken up the opportunity. For five people they had simply not been given a start date yet. Four people felt that they already had a lot of knowledge of the disease due to family history, although one person also said they were "put off having to go to the hospital" and one also said they forgot to attend. A further three people had either been ill at the time or had been going through “a lot of trauma” and did not feel like they were in a position to attend.

> “I was booked on the DESMOND course but took ill so I am waiting for a new appointment”.
>
> “Depression; couldn't face a room full of people”.
>
> “I already know about diabetes because my mother has it. I felt I had enough information”.
>
> “I was determined to sort it out myself such as being involved in research to learn more about it. Also, my wife attended the DESMOND as she also has diabetes so I know a lot about it.”
>
> “My brother and sister also both have type 2 diabetes and they told me everything”.

These patients were also asked whether they would consider attending a course in the future and what might encourage them (excluding those five who were waiting to go on the course). One person said that they were going to go on the dietician group course instead, another said they would go if it involved research, a third said their illness had improved so they would consider it and a fourth said that location was key as they “have difficulties with public transport, especially buses and get panic attacks”. Two people who felt that they already had knowledge of the condition said that nothing would encourage them.

> “No, I’m 80 and I seem okay”.
>
> “I don’t think I would go as I control it well”.

3.3.3 Living Well, Taking Control

Of the 75 people (79.8%) offered a course seven people (9.3%) were offered the Living Well, Taking Control course; all took part in the course. Four people had been referred by their GP or Practice Nurse, one person had been referred by a Health Trainer based at HealthWORKS and another volunteered at HealthWORKS so heard about the course, one person could not remember. They attended either the HealthWORKS building in Benwell, the Lemington Centre or the Sure Start Centre in Fenham.

In terms of expectations of the course, two people wanted “help to manage it”, one wanted advice, another to learn about diet, one person said the nurse told them exactly what to expect and the other two had no expectations. All felt that their expectations had been met and were very positive about the course.

> “The different aspects like food and exercise was interesting and informative”.

> “I went every Monday for six weeks and it was very good. They were all lovely. They weighed us, measured us, checked our bloods and they ran cookery classes”.
>
> “It’s a good approach with a lot of visual information…The group has been really useful for stress control and for recognising a range of symptoms that other people were describing, because I had been thinking I was going mad. It was so helpful to hear people talking about anxiety and I could think to myself ‘It’s not just me. It does happen to other people’. It was interesting listening to people from other cultures and hearing about different foods. There is a lot of home cooking in south Asian communities and so people don’t always know how to work out what’s in the food - there might not be any label. The healthy eating cooking sessions are very good because I’ve picked up things like using fromage frais and low fat yoghurt”.

All attendees receive ongoing support in the form of a ‘buddy’ who keeps in touch with them at regular intervals and all received a booklet to take home and complete in their own time. They all felt that the support they had been given was useful and one participant preferred this support to that provided on the DESMOND course. None requested any additional support or information.

> “Yes, we have a catch up every three months and my buddy keeps in touch with me in between too. It's excellent. At DESMOND we were given information but I don't know where it is, I prefer the buddy system”.
>
> “Yes, a booklet called 'Living Well, Taking Control' that you can fill in”.
>
> “You get all of the information and there’s support from your health buddy to make changes. It’s motivating”.
>
> “Yes, my mentor is great”.
>
> “I have to say it worked for me. It was a lot more explanatory than what I got from the nurse. It helped me a lot and I've lost weight which I wouldn't have done if I hadn't been on the course”.

3.3.4 Non-attendees

In total 19 people (20.2%) had not been offered either the DESMOND or Living Well, Taking Control courses. Of these, 11 (57.9%) had had the condition for less than 12 months and the remainder (42.1%), for between one and five years. Sixteen (84.2%) said that they would consider attending a course if they were offered the opportunity in the future; one said they would not attend and two did not answer.

3.4 Managing the condition

Participants were also asked whether they do anything to manage their condition themselves. Only nine (9.6%) had not made some sort of lifestyle change since being diagnosed with diabetes. Changes to diet were most frequent followed by starting to do some exercise or increasing exercise.

Type of self-management	**No. of responses***
Changes to diet	77
Exercise	28
Monitoring blood sugar levels	3
Stopped smoking	1
Take herbal remedies	1

*Participants could give more than one response

> "I have cut out sugar and alcohol and I'm careful about the type of food I eat and what is in it".
>
> "I cut out fresh orange, eat muesli, soya milk, rye bread - watch my diet generally".
>
> "I realised it's not what I eat it's how much when they showed me the plates on the course so I've cut down how much I eat".
>
> "I go to the gym, I take the dogs for three hour walks and I changed my diet".
>
> "I watch my diet and I do exercises at the gym. I have lost weight. I think at the next test I might be free of diabetes".

Those nine who stated that they did not manage their condition were asked what would help them to do so. Five people felt that nothing would help them, one requested diet information and another specifically recipes and another participant asked for exercises which were sympathetic to the conditions they had. One DeafBlind participant asked for "more formal information, related specifically to me and my circumstances".

Forty-three people (48.9%) were supported by either family members or friends to manage their condition. They were asked whether they felt that their family and friends needed anything to help support them. Twenty-nine people (67.4%) felt that they did not need anything and four (9.3%) people did not know. The remaining 10 (23.3%) came up with the following suggestions:

Help to support	No. of responses*
Information about diet	6
Information specific to partners/supporters	2
To accompany the patient on a course	2
General information about diabetes	1
Lifestyle information	1

*Participants could give more than one response

“My wife needs lessons on sugar in food and portion sizes”.

“They find it difficult to help because they don't understand the eating pattern 'you can have a little' or 'I know diabetics who eat this' 'well I won’t have any then' and you feel guilty”.

“It would be good to have a leaflet for partners and relatives on how to support us and what it means to have a diabetic partner”.

“He would have liked to have gone to a course as well”.

3.5 Preferences of proposed changes to education courses

Participants were also asked to consider the three proposed diabetes education course formats and decide which, if any, they felt would best suit them if they were to consider attending a course in the future.

Preferred course	No. of responses*	% of participants
Option 1	34	36.2
Option 2	49	52.1
Option 3	9	9.6
No preference	1	1.1
None	2	2.1
Total	95	

*One participant could not choose between option 1 and option 2

3.5.1 The preferred option - Option 2

More people would prefer to attend a course which follows the format of option 2. Participants were asked why they would choose option 2, two patients (4.1%) did not give a reason; the remaining 47 patients’ (95.9%) reasons were as follows:

Reason	**No. of responses***
Prefer a community location	27
Prefer shorter sessions over a longer period	22
Opportunity to meet other people	11
Flexibility of the times	7
Option of the course in other languages	7
Had a positive experience at the LWTC course	3
No interaction with computer course	7
Don’t have a computer	6
Don’t like using computers	2
Don’t like e-learning	2
Wouldn’t commit myself to the computer course	1

*Participants could give more than one response

People who chose option 2 did so for two primary reasons. They preferred to attend a course that was based in their community so that they did not have to travel too far, were in a familiar setting and did not have the anxiety of going to hospital. They preferred to have more sessions that were shorter in length, which would give them the opportunity to take the information in and formulate questions for the next session and be given the information in more manageable chunks.

> “Bringing sessions out to places like here [venue of regular social group supported by the local authority] means it would get to people with a diagnosis of diabetes and their family members, as well as friends who might need to know things because there is diabetes within their families, or to be able to avoid developing diabetes.”
>
> “Location is important to me, has to be easy to get too. Shorter sessions should also mean I can take more in and have more time to think of questions”.
>
> “It would be in a community location and at better times of the day. You'd also get to meet other people with their experiences of diabetes and know you're not alone”.
>
> “I like the fact that it is shorter blocks and is local”.
>
> “This will give you more time to digest the information and to get to know the group. The course I went on was rushed (DESMOND) - it would be better if it took longer with more time to digest the information and ask questions”.
>
> “Brain freezes after a while! Three sessions gives chance to think things through and bring to the next session. If in a local community centre, chances are people attending live nearby and potential for peer support”.

Eleven people (22.4%) also chose the course because it would give them the opportunity to meet people, including those from their local community and share ideas and knowledge. The longer course duration would allow time to get to know other attendees.

> "The shorter sessions with a longer course length would be great to build up that relationship with the group and go through the journey. The shared experience aspect is very important and a longer course would be better for that"

> "Option would be for shorter sessions over a longer time so you can get to know people and exchange diets".

For seven people (14.3%) the flexibility of the times was their reason for choosing option 2 because they worked or had family commitments to fit around it.

> "I have four children so I need more options of times and option 2 has that".

> "Out of work hours is best for me".

For a further seven (14.3%) having the option of a course available in other languages was important. From HAREF's research with black and minority ethnic women, all highlighted the value of bilingual workers as language can be a significant barrier to the DESMOND programme for some people.

Participants also gave reasons that they would not choose Option 3 specifically; they did not like the fact that there would be no interaction with other attendees or course leaders or did not have a computer or like to use it. Two people did not think e-learning was very good and one participant felt that they would have no motivation to complete the course if it was all online.

> "I would get tired with the longer courses and I can't use computers".

> "I would put it off and it would never get done and there is no chance to ask questions or there would be a delay".

> "The computer course would result in not meeting people so won't get advice from others".

In terms of what they would like to learn from the course, six people (12.2%) did not know, the remaining 43 participants (87.8%) suggested the following content:

Course content	**No. of responses***
Diet	24
Same as DESMOND	7
Exercises	7
How to manage the condition	6
Causes of diabetes	4
How to improve their condition	3
Information about medication	3
The option to ask questions	3
Practical advice	3
Same as LWTC	2
Treatment available	2
Other classes to attend	2
Everything	1
Effects of the condition	1
Facts about diabetes	1
Lifestyle changes they could make	1
Practical implications of the condition	1
Seriousness of the condition	1
Weight loss	1

*Participants could give more than one response

Diet information was by far the most commonly mentioned. People wanted to learn about what foods they can and cannot eat and in what quantities and one participant suggested having a rating system. People also wanted information on how to stop eating the wrong foods and one patient asked for information on how to eat the right foods on a low budget.

> "Help to make me to eat the right foods to control my blood sugar".
>
> "What foods to eat, the seriousness of diabetes and how to stop eating the foods that are bad for you".
>
> "I would want a diet sheet with good and bad foods and lots of information".
>
> "The same things that were covered on DESMOND but a bit more information on foods you could eat like a ratings system".

General information on how to manage their condition was also mentioned including what to do if a patient's blood sugar became raised and for HAREF participants in particular, information on how and where to exercise was important.

> "Just how to manage my diabetes and stabilise the condition; I want to prevent problems in the future".

In terms of practical advice one participant felt that the course should be more interactive to keep people's interest and encourage them to start making changes to their lives.

> "I think it would be a good idea, instead of talking about diet to do a demonstration of cooking a healthy meal or give people a task like a shopping list to go and buy ingredients and try to make a meal at home before the next session".

One participant also felt that the course should cover how having diabetes may affect non-health related parts of their lives.

> "Maybe why it happened and what you can do to improve it. For me it's not lifestyle. Maybe information about how it will affect our life insurance or our travel".

Another D/deaf participant felt that the course should be focussed on imparting facts about diabetes and not the sharing of experiences of attendees as this resulted in the course they had previously attended overrunning and their interpreters having to leave before all of the information had been given.

> "Facts. My experience of the two sessions were people wanting to share their experiences, not that there is anything wrong with that, but I came to learn facts not to hear how someone finds it difficult to eat because of children or how good someone has lost so much weight since diagnosed. Therefore the facilitator had to rush and omit certain parts of course and over ran but the interpreters only booked for three hours and had to leave before the facilitator had completed their list".

Participants were also asked whether there were any aspects of this course that they would change. Thirteen people (13.8%) said that they would make the following changes:

Course changes	**No. of responses***
Duration	5
Different location	3
Provide follow-ups	2
Smaller group size	2
BSL interpreters	2
Better management of sessions	1
Online	1
Information provided in Plain English with visuals	1

*Participants could give more than one response

Three people requested that the sessions mirrored those of DESMOND, being longer and spread over two weeks. Two participants felt that there should be more sessions and one specifically stated 10 sessions, an hour in length.

> "I would still prefer to have fewer longer sessions like DESMOND rather than more as it is quicker".
>
> "Instead of it being six sessions, it should be something like 10 sessions of one hour so you can have more of that shared experience and support each other through the journey".

Three people suggested a different location. Two people said that they would prefer to have the course at the hospital and another wanted the course to be held at Deaflink as it is easier to access and easier for BSL.

Two wanted follow-ups to be provided after the course had ended.

> "The group keeps on meeting after we've had the information, and people can encourage each other to exercise and eat different things and not eat as much."

Two also requested BSL interpreters to be available on the course and to support D/deaf people further, one person requested information in Plain English with lots of visuals e.g. illustrating changes in the thickness of blood by showing water on its own and water with different concentrations of sugar in it, going through a straw.

Participants were also asked whether there were any aspects of other courses they would like to include in this one, six people (12.2%) suggested:

Aspects of other courses	**Reason**	**Course from**
Have the option for people to access some of the information online in addition to the course (x3)	Access to trusted information online to refer back to and complement the course	Option 3
Giving the same information in different formats	Helps to reinforce the messages	Option 1
Have it in a hospital setting	Feel more confident there	Option 1
Include a cookery session about how to reduce sugar and what to substitute.	Helps keep people's interest and gives them practical information to take away	LWTC

Thirty-nine people (47.9%) expected to be given information to support them once the course was finished. They requested the following information:

Information	No. of responses*
Format	
Leaflets	16
Access to a helpline	9
Follow-ups	8
Manual	7
A mentor	3
Contact details of someone	2
Online information	2
Support groups	2
Email address	1
Blood sugar test kits	1
Content	
Diet information	4
Future developments in diabetes management and treatment	2
Exercises/classes	2

*Participants could give more than one response

In terms of the format of the information the majority of people would be happy with things they could have in their own home such as leaflets or a manual to read and work through.

> “Something I could take away to read - I think it's important to be able to take it away as you could forget things and you need time to digest”.
>
> “Just if there's new information and leaflets to be able to send those out”.

Other people requested the ability to contact people either face-to-face in the form of mentor or buddy who they stayed in contact with once the actual course was finished or support groups they could attend, or by telephone or electronically so that they could ask questions when they needed to.

> “Information pack and access to a helpline if I had any questions”.
>
> “I would want a buddy system like LWTC - The 3 month catch ups and the buddy system is brilliant”.
>
> “Contact details of someone or a helpline”.

3.5.2 Option 1

Thirty-four people (36.2%) would prefer option 1, again one person did not give a reason but the remaining 33 gave the following reasons:

Reason	No. of responses*
Prefer longer sessions over a shorter period	23
Had a positive experience on DESMOND course before	7
Prefer a hospital location	5
No time commitments so daytime is fine	5
Opportunity to meet other people	4
Don’t have a computer	5
No interaction with computer course	3
Don’t like using computers	2
Don’t like e-learning	1
Wouldn’t commit myself to the computer course	1

*Participants could give more than one response

By far the most common reason (69.7%) for choosing option 1 was the short duration of the course, which takes place over two mornings or afternoons.

> “I'd prefer to get it over and done with in longer sessions”.
>
> “For me, it would be better to get the time off work for just a couple of sessions than a whole course”.
>
> “There are less sessions with this option so I’m not going back and forth”.
>
> “I think I would benefit from a more in-depth session over a shorter period of time”.

Also, seven people (20.6%) had previously attended the DESMOND course and felt it had worked well for them or knew of someone who had had a positive experience there.

> “The teaching on the course was good and it’s good to do it all at once”.
>
> “Happy with the structure of DESMOND but just felt the content wasn't great”.

As with those who chose option 2, participants commented on why option 3 would not suit them. Again they do not have a computer or do not like using one, did not like the fact that there would be no interaction with other people or did not feel that they would commit to the course under their own steam.

> “I don’t have a computer so option 3 is no good for me”
>
> “Option 3 wouldn't work because I want to be able to ask questions”.

In terms of what they would like to learn from the course, five people (14.7%) did not know, the remaining 29 participants (85.3%) suggested the following content:

Course content	**No. of responses***
Diet	10
Effects of the condition	6
How to manage the condition	3
General information	3
How to improve/reverse their condition	3
Same as DESMOND	2
Information about the different blood sugar tests	2
Causes of diabetes	1
Symptoms of diabetes	1
The option to ask questions	1
The link between diabetes and statins	1
Diagnosis	1
The biology of having diabetes	1
Exercises	1
Weight loss	1

*Participants could give more than one response

As with option 2, diet information was the type most commonly requested. Some people simply wanted general information about the best foods to eat whilst others wanted more specific information about food labelling and the glycaemic index.

> "The percentage of sugar to eat per day. Something simple what you can and can't eat in a less technical way".
>
> "I would like guidance on food because food labels remain a mystery to me".
>
> "I'd want to learn more about the glycaemic index to find a list of good and bad foods".
>
> "Portion sizes, list of sugars and carbs in common foods, high risk foods, foods that have a green light, information on sugars in alcohol and alternatives".

Two people wanted information on the different blood sugar tests available.

> "Lots but in particular to know more about the various tests and how they work".
>
> "I would like more information on blood testing and urine as a comparison".

One participant wanted to know more about the link between taking statins and developing diabetes and one wanted to understand whether their diagnosis could change.

> "I liked the content of DESMOND but I think there should be something in there about statins and their effects and an opportunity for questions and answers. I was made to feel stupid when I said about statins".
> "Some information on what happens if count goes down, are you still diabetic?"

Participants were also asked whether there were any aspects of this course that they would change. Twelve people (35.3%), all of whom had previously attended a DESMOND course said that they would make the following changes:

Course changes	**No. of participants**
Different location	3
Content	3
Session format	2
Duration – too short	1
Larger room size	1
Times too restrictive	1
Course leaders	1

Three people suggested a different location to a hospital, two thought a location closer to home, such as their GP practice would be better and one felt that the “General Hospital site seems outdated because it is half closed”.

For three people who had previously been on the DESMOND course, the content was an issue. One participant wanted more detailed information, another wanted information about statins and diabetes and the third questioned the validity of some information they had been given.

> “What the dietician tells you - I disagreed with the content and the view of high vs low carb diets”.

In terms of the format, one person wanted time to ask questions and another disliked having to speak in front of a group of people.

> “I didn't like the round robin introductions on the course as I didn't want to speak in front of everyone”.

Participants were also asked whether there were any aspects of other courses they would like to include in this one, six people (17.6%) suggested:

Aspects of other courses	**Reason**	**Course from**
Have the option for people to access some of the information online in addition to the course (x3)	Access to trusted information online to refer back to and complement the course and learn at your convenience	Option 3
More flexible times (x3)	Better for people who work to have more options	Option 2
Have it at home	More convenient	Option 3

Thirty-three people (97.1%) expected to be given information to support them once the course was finished. They requested the following information:

Information	**No. of responses***
Format	
Leaflets	20
Access to a helpline	3
Follow-ups	3
Online information	3
Manual	2
Blood sugar testing	2
Contact details of someone	1
Content	
Diet information	6
Exercises/classes	3
Future developments in diabetes management and treatment	2

*Participants could give more than one response

Leaflets with any updated information were by far the most commonly mentioned. Several people requested access to a helpline to answer queries or online information they could refer back to. Three people felt that follow-ups should be offered after the course had finished.

> “Regular contact afterwards with booklets and leaflets. Also that the bloods monitoring should be more stringent rather than every 6 months. Should also get back together at regular intervals too”.

3.5.3 Option 3

Nine people (9.6%) chose option 3, the computer based course and the main reason was because they could do it in their own time. Being able to do without leaving the house and without having to join a group of people was also appealing.

Reason	No. of responses*
Can do it in my own time	6
Can do it at home	4
Can do it on my own	2
It is shorter than options 1 and 2	1
Can read the information over and take time to understand it	1

*Participants could give more than one response

> "The computer would be best for me - I can do it in my own time, I don't have to go anywhere, I don't have to sit in a room with lots of strangers, its just more convenient".
>
> "It is easier for myself. I can access it at home and I am on the computer all the time, even when I am on holiday".
>
> "I haven't always got the time to be sitting around, my days are busy. I also like to use my computer, option 3 is more flexible and lets me do it when I want to".
>
> "When learning in a course via BSL, easy forget after the course and prefer on the computer so can read again and again repeat but want BSL on the computer to understand diabetes information better. I have a computer at home".

In terms of what they would like to learn from the course, one person did not know, the remaining participants suggested the following content:

Course content	No. of responses*
Diet	6
General information	2
How to manage the condition	1
Exercises	1
Weight loss	1

*Participants could give more than one response

As with options 1 and 2, most people wanted to learn about diet.

> "I would like more information on food intake and contents. I do read the back of packets for cholesterol and sugar but it would be good to have help with it".
>
> "I'd want to know about my diet - alternative foods to high sugar foods".

> "I would like to learn how to manage diabetes, what to look out for and about diet. I would like to exercise with people with the same condition and management of it. I did join the gym but it was too expensive so it would be good if the government could support this".

Participants were also asked whether there were any aspects of this course that they would change. Only one person requested that it "be tailored to people's needs and provide information before hand to prepare for the course".

No one suggested including aspects from any other courses in this one.

Seven people (77.7%) expected to be given information to support them once the computer-based course was finished. They requested the following information:

Information	No. of responses*
Format	
Booklet	4
Online information	2
Access to a helpline	2
Meeting other diabetes patients	1

*Participants could give more than one response

> "A reference that I could check at any time. Phone numbers and maybe a website to check".
>
> "Just a booklet - something as a reminder".

3.6 Preferences of education courses generally

In addition to being asked their views around specific course formats, participants were also asked generally what their preferences were for a course location, leader, group type, time and duration.

Preferred course location	No. of participants	% of participants
Community location	53	56.4
Hospital	18	19.1
No preference	19	20.2
Home	4	4.3
Total	94	100.0

Over half of people would prefer to attend a course in a community location and they gave their reasons for this choice as follows:

Preferred course location	No. of responses*	% of responses	% of participants
Convenience	25	40.3	47.2
Feel uncomfortable in a hospital environment/ more comfortable in a community setting	12	19.4	22.6
Better parking than hospital	8	12.9	15.1
Reach other community members	6	9.7	11.3
Easier to get to by public transport than hospital	4	6.5	7.5
Opportunity to meet people from your community	4	6.5	7.5
May have gym facilities attached	1	1.6	1.9
General Hospital site feels outdated	1	1.6	1.9
Easier for BSL	1	1.6	1.9
Total	62	100.0	

*Participants could give more than one response

Just under half of patients (25) felt that it would simply be more convenient than travelling to a hospital.

> "It is easier to get to if it is local".
>
> "Because of the shorter distance and less travel, would be more convenient".
>
> "Easier to get to if it's in the east end".

One fifth quarter of people (12) said that they felt uncomfortable in a hospital environment or felt more comfortable in a community setting.

> "Community setting is more pleasant. Hospitals are depressing and I've had enough of hospitals".
>
> "I think people feel more at ease in a non-hospital setting".
>
> "I see enough of hospitals!"

A further eight people (15.1%) felt that parking would be easier in a community setting.

> "Parking at the hospital is difficult and expensive".
>
> "Not at a hospital, they all have poor parking".

Six HAREF participants felt that a community setting would be good because other family members and friends may be able to attend, as may other people with the condition.

> "Bringing sessions out to places like here (venue of regular social group supported by the local authority) means it would get to people with a diagnosis of diabetes and their family members, as well as friends who might need to

> know things because there is diabetes within their families, or to be able to avoid developing diabetes”.

Eighteen people (19.1%) said they would prefer a hospital setting and gave their reasons as follows:

Preferred course location	**No. of responses***	**% of responses**	**% of participants**
Convenience	9	42.9	50.0
Familiar location	4	19.0	22.2
Facilities available	3	14.3	16.7
Emphasises seriousness of condition	3	14.3	16.7
Experts on site	1	4.8	5.6
Parking available	1	4.8	5.6
Total	21	100.0	

*Participants could give more than one response

Again the convenience of a hospital location was mentioned most frequently, followed by the familiarity of a hospital setting as patients had spent time there before. Three people felt there were better facilities available in a hospital setting and another three felt that having a course in a clinical environment would help to emphasise the seriousness of the condition.

> “Don't want to travel very far because I am elderly but I can get to General Hospital”.
>
> “Because of timing and I am familiar with where it is”.
>
> “I think they would have better equipment”.
>
> “It’s a serious business and should be dealt with in a serious location”.

Everyone was happy to have the sessions run by nurses or healthcare workers providing they were specialists or knowledgeable about diabetes although one D/deaf person said “as long as the nurse has deaf awareness training and training materials to reflect that”.

Patients were also asked whether they would prefer to attend a group session where participants were similar in gender, age or lifestyle for example. The majority of people (72, 76.6%) had no preference for group type or stated that they would prefer a mix “so you get different views and opinions”. The remaining 22 participants (23.4%) requested group types as follows:

Preferred group type	No. of participants
Community-based groups	6
Age groups	4
Similar blood glucose score groups	3
Dislike groups	2
Small groups	2
D/deaf people	2
Accessible groups	1
Single gender groups	1
No groups	1
Total	22

All HAREF participants felt that having community-based groups was important so that family members and friends could also attend. Splitting attendees by age or their level of diabetes was also mentioned. Two people said they disliked groups and one person thought that the education should be entirely private. Two people requested a small group size as they would feel more comfortable and able to speak out, two people would prefer sessions with other D/deaf people, one person wanted the option of single gender groups and one simply wanted the group to be accessible as they “found it hard to hear”.

> “I would like to be a group with people who have been diagnosed a similar time or are at the same stage of diabetes as me”.
>
> “By score so all borderline or symptom free people are together”.
>
> “I would prefer smaller groups; I can be a bit shy”.

In terms of times and days that would suit people to attend a course 27 people (28.7%) had no preference and four people (4.3%) said that they worked but as long as they had plenty of notice to request time off, any time would be fine. The remaining patients requested the following times:

Times	No. of participants
Daytime	25
Mornings	16
Afternoons	11
Evenings	5
Total	55

Some also requested specific days:

Times	No. of participants
Weekdays	8
Mon, Tues, Fri	3
Tues, Wed, Thurs	3
Mon, Tues, Thurs, Fri	2
Mon, Tues, Wed, Sat, Sun	1
Mon, Tues, Wed, Thurs	1
Mon, Tues, Wed, Fri	1
Mon, Tues, Thurs	1
Mon, Wed, Thurs	1
Mon, Thurs, Fri	1
Wed, Thurs, Fri	1
Mon, Wed	1
Mon, Fri	1
Tues, Thurs	1
Thurs	1
Fri	1
Total	28

Participants were also asked their preference for more sessions that were shorter in length to fewer sessions that were longer in length.

Preferred sessions	No. of participants	% of participants
Longer but fewer	41	43.6
Shorter but more	35	37.2
No preference	16	17.0
Not applicable	2	2.1
Total	94	100.0

As can be seen from the table above, 16 people (17.0%) had no preference and a further two people (2.1%) said that they would do the computer course so the question was not relevant to them, but longer and fewer sessions were most frequently requested. One participant said there should be a maximum of three sessions and another who had attended the DESMOND course suggested that “more sessions could lead to more DNAs” as they were surprised by how many people did not come back to the second DESMOND session.

Those who would prefer shorter sessions felt that they would be better because “so you can go away and think about questions” and it “allows more time for information to sink in”. Two people made suggestions about the length of sessions – no longer than two hours or about 45 minutes long.

Participants were also asked how else they might like to receive education around their diabetes. Twenty-two people (23.4%) suggested the following:

Format	No. of participants
Online	6
Electronically	3
Given by practice staff	2
At home	2
Leaflets	2
DVD	2
Telephone application	1
Books	1
Buddy system	1
Through the post	1
On television	1
Total	22

Six people requested online information. Three people felt that there should be a website that complemented the education course which attendees could use to review the information they had been given and be provided with more in depth information if they wanted to look at it in the future. It could also include a forum where people could ask questions and share information with others. A further three people simply suggested online information as was described in option three.

> "Trusted website that links to the courses. So it would have the course material, FAQs which are regularly updated and some sort of forum to be able to share information with others attending the course - things like recipes and tips".
>
> "I would like a website with trusted information and all the information from background to what happens in the future. It should have proper information about the glycaemic index foods as that's nowhere to be seen. Have all the basic information on there from the courses but have more for people that want to know more".

Three people wanted information given to them electronically, so that they could get regular emails in a newsletter style format.

One person wanted their GP to communicate the education information to them and another, the Diabetes Lead in their practice. A further two people wanted to be given the information at home, two requested leaflets and one wanted information in the post. Two people thought that being given a DVD to watch would be a useful way to relay the information.

3.7 Barriers to attending a course

Participants were also generally asked whether anything would prevent them from attending a diabetes education course. All but one participant gave a response to this question.

Barriers	No. of participants	% of participants
Nothing	33	35.5
Timing of course	10	10.8
Illness	10	10.8
Accessibility issues	8	8.6
Work commitments	7	7.5
Course location	5	5.4
Personal commitments	3	3.2
Being on holiday	3	3.2
Caring commitments	2	2.2
Experience of a previous course	2	2.2
Hospital appointments	2	2.2
Short notice	2	2.2
Lack of information about course	2	2.2
Computer format	1	1.1
Parking	1	1.1
Bad weather	1	1.1
Not applicable	1	1.1
Total	93	100.0

*Participants could give more than one response

For one third of people (33), nothing would stop them attending whereas one person said that they would simply not attend. For just over one-in-ten (10) the timing of the course would be a barrier and for a similar number (10) illness would prevent them from attending.

> “I wouldn't go if they were only available in the evenings”.
>
> “Health related - just if I wasn't well”.
>
> “It would depend on the travel to the course”.

Eight people (8.6%) would be restricted by accessibility issues; namely, not having the course provided in another language or having no spoken language support or an interpreter available, not being physically able to access the building due to a mobility chair and for the participant who was DeafBlind:

> “I rely on a DeafBlind manual interpreter. I need a minimum of double the usual time for communication. I would not be able to join in group sessions”.

Seven people (7.5%) would be restricted by work commitments.

3.8 Encouraging people to attend a course

Participants were asked whether they had any suggestions about what might encourage a diabetes patient to attend an education course. Thirty-six people (38.3%) did not have any ideas, however the remaining 58 (61.7%) suggested:

Suggestions	No. of participants	% of participants
Stress seriousness of condition	13	22.4
Tell patients the benefits of the course	9	15.5
Proactively inform people language support will be available	6	10.3
Have the course endorsed by previous attendees	5	8.6
Stress that patients can recover or get better	4	6.9
Offer transport to the venue	3	5.2
Keep the sessions short	3	5.2
Advertise the courses in community centres	2	3.4
Make the course interesting	2	3.4
Keep it light-hearted	2	3.4
Normalise the condition	2	3.4
Incentives to attend	1	1.7
Have their GP endorse it	1	1.7
Inform people who the course leader will be in advance	1	1.7
Make home visits	1	1.7
Personalised invitation letter	1	1.7
Allow someone else to attend with the patient	1	1.7
Information in Plain English	1	1.7
Total	58	100.0

Participants felt that the seriousness of having diabetes needed more emphasis either within the letter or during discussions with the Practice Nurse or whoever was responsible for highlighting the course.

> "Well, since I've been diagnosed I have to say I don't feel any different so for people like me I think they'd maybe need a shock to make them go on it - a leaflet explaining the things that could happen to you if you don't look after your diabetes".
>
> "I work in a shop a couple of days per week and when I was diagnosed with diabetes I was devastated. I was absolutely terrified of going blind. People who come in the shop were asking how I was and when I told them, they would just say 'oh, don't worry, it's just diabetes'. That's the problem - you need to get through to people how serious it is and make them realise it's not 'just' diabetes".
>
> "Stress how important it is and how diabetes can affect people if it is not managed – the effects on people's eyes and feet because a lot of people don't know about that - you need shock tactics".

Nine people (15.5%) felt that the benefits of the course needed to be more clearly advertised.

> “People think they're wasting the time but it's really good so just stressing how helpful it would be to them”.

> “It’s for your own health benefits”.

Six HAREF participants (10.3%) felt that proactively telling patients that there would be language support available would encourage black and minority ethnic communities to attend a course.

Others suggested that the course be endorsed by previous attendees and this endorsement be included in the leaflet about the course.

> “Endorsements from people who have taken part in the course. On the leaflet that is sent out to you about DESMOND, there should be patients' stories on there encouraging others to go”.

Four people (6.9%) felt that there should be more emphasis on the fact that patients can recover or improve their condition and that the course can help them do so.

> “If you're told when you're diagnosed that if you go to the courses you will feel better and you'll potentially get better. They focus on the negatives far too much and try to scare people which doesn't work”.

3.9 Other comments and suggestions

Participants were also given the opportunity to comment on any other aspects of their diabetes care.

3.9.1 Education courses

Six people (6.4%) who had not yet been on a course said they were looking forward to attending as they wanted more information as soon as possible.

> “Would have liked to have gone on the Desmond course sooner but there is a long waiting list”.

> “Bit in the dark, feel a bit nonchalant, would like to know how to stop it getting worse”.

One participant suggested that attendees should be given appointments to attend a course rather than being asked to arrange a time themselves as people do not always act immediately.

> "I was sent a letter inviting me to make an appointment when they found I had diabetes, but really they should have sent a letter with an appointment as it took me a month or so to go. If they'd given me an appointment I would have been seen sooner and given all the information sooner".

3.9.2 Dietician

In terms of the dietician session, one participant felt that the information was not personalised enough.

> "I was given an appointment with a dietician. It was useless as I have Crohns disease so I can't eat fruit or vegetables. She didn't listen to me; she just had her spiel and wanted to say it".

3.9.3 Monitoring

One participant requested that they get a print out of their blood tests after each monitoring appointment.

3.9.4 Prevention

The remaining four comments (4.3%) related to preventative measures the GP could help patients take to reduce their chances of developing the condition. One person requested that their GP distribute testing kits so that people could themselves check whether they had the disease. Another would have "liked to have been warned about the possibility of developing type 2 diabetes". A further two people who had been 'borderline' felt that they should have been offered a course around prevention.

> "I would like to have been offered the course sooner, i.e. before I actually got diabetes as I had three years of being borderline and I could have tried to do something about it through diet if I had had the information. - I had been following a Slimming World diet where you ate loads of carbs which I think didn't help!"

> "Why wasn't I given all this information when I was told I was borderline diabetic? This course would have been even more useful a year earlier when I was told I was borderline diabetic. Then I could maybe have prevented becoming diabetic".

3.10 Summary

3.10.1 Diagnosis and initial information

Of the 94 patients who took part in the research, 44.7% (42) had been diagnosed within the last year and 55.3% (50) had had their diagnosis for between one and five years. The majority of people had no symptoms of the condition and were unaware that they had the condition as it was either discovered after a routine blood test, they had presented at their GP with an unrelated illness or it was picked up during treatment for another condition they had.

Four-fifths of people (76, 80.9%) received some information at their initial diagnosis about next steps, diet and weight loss, either in the form of written or verbal information. Thirteen people (13.8%) did not find the information useful and this was mainly due to the inaccessibility of it. Three HAREF participants found it difficult to access because of their level of English skill. One person who was blind was given a leaflet and another who was D/deaf found the language difficult to understand. The majority of those who did not receive information would have liked some (13 of 18, 72.2%) and information on diet, calories and recipes (taking into account the sorts of food that people cook across communities) was most frequently requested.

3.10.2 Experience of educational courses

Seventy-five (79.8%) had been offered the opportunity to attend either the DESMOND or LWTC educational course and two of those people had been offered both. Of this group 61 (81.3%) attended a course although two people chose not to attend the second DESMOND session.

3.10.2.1DESMOND

Attendees

Fifty-six people (82.4% of those offered) attended DESMOND. Referred by their GP or Practice Nurse they attended the Diabetes Centre, Brunton Park Health Centre or Molineux Street NHS Centre. Most people had expectations of the course and these were around being given general information about the condition or information about diet and foods to eat or cut out. Nearly two-thirds of people (24, 61.5%) felt that their expectations had been met and their experience was a positive one. They enjoyed meeting other people, sharing experiences, the course leaders and the format. Those 13 (34.2%) who felt expectations had not been met cited the skills and knowledge of course leaders, the content of the course being too much or too little information or not personalised, the intimidating large group size or the length of the session. One D/deaf participant was unhappy as they learnt that despite a support group being in operation in the city, there was no funding for D/deaf people to access it. Another three people commented that the sessions were too long, there were no refreshments and for one D/deaf person the fact that it had taken eight months to get onto the course due to interpreter bookings/fee issues. Also, for two HAREF participants there was a language barrier; they felt that it was very difficult to understand the information because the session was long and the language was complicated.

Three-quarters of people (42, 75.0%) had been given ongoing support once the course had ended in the form of a manual/booklet to work through and urine blood glucose test kits. Three people said they were referred to HealthWORKS for lifestyle support and exercise. Eight people (19.0%) did not find the information useful due to the lack of detail within it. Seventeen participants (30.4%) requested other support, mainly around having follow-up session to check the progress of attendees within a year of the course. Six HAREF participants respondents requested follow-up sessions within their community-based groups to top-up messages about diet changes and where to go to exercise.

Non-attendees

Those 12 people (17.6%) who were offered the course but did not attend described their reasons. Five were simply waiting for their start date, four people felt they knew enough about the condition and three people had been unwell. All but three said that they would consider attending in the future; two felt that they knew enough and one said that they were happy to just go to the dietician.

3.102.2LWTC

Seven people (100.0% of those offered) attended the LWTC course. Referred by either their GP, Practice Nurse or a Health Trainer or finding out about it themselves, they attended the HealthWORKS building, Lemington Centre or Fenham Sure Start Centre. All felt their course expectations had been met and were very positive about it citing the interesting information and practical sessions in particular. They all received ongoing support in the form of a buddy who keeps in touch with them at regular intervals and received a booklet to take home and complete.

3.10.2.3Non-attendees

Nineteen people (20.2%) had not been offered the opportunity to attend an educational course and of these 11 (57.9%) had been diagnosed less than 12 months ago. Sixteen (84.2%) said they would consider attending in the future, one said they would not attend and two D/deaf participants did not answer.

3.10.3 Managing the condition

All but nine participants (9.6%) had made some sort of lifestyle change since being diagnosed, with the majority improving their diet and others exercising. Of the nine, five people said nothing would help them manage their condition, two requested more personalised information or exercises sympathetic to their disability or condition, one requested diet information, another recipes. Ten people (23.3%) requested something to help their family to support them with their condition mainly in the form of diet information.

3.10.4 Preferences of proposed changes to education courses

Option 1 - Structured DESMOND course
Option 2 - Within a community setting
Option 3 - Computer-based course

Participants were asked to consider which of the three proposed diabetes education course formats would suit them best if they were to consider attending a course in the future. The following options were chosen:

Preferred course	No. of responses*	% of participants
Option 1	34	36.2
Option 2	49	52.1
Option 3	9	9.6
No preference	1	1.1
None	2	2.1
Total	95	

*One participant could not choose between option 1 and option 2

3.10.4.1Option 2

Option two was the preferred choice for the largest number of participants. The two main reasons for choosing this option were the preference for attending a course in a community setting so that they did not have to travel too far, were in a familiar setting and did not have the anxiety of going to hospital. They also preferred to have more sessions that were shorter in length, which would give them the opportunity to take the information in and formulate questions for the next session and be given the information in more manageable chunks. Eleven people (22.4%) liked the chance to meet people, including those from their local community and build up a rapport over a period of time and share ideas. Seven people liked the flexibility of the times and for a further seven having the course available in other languages was very important. All HAREF participants highlighted the value of bilingual workers as language can be a significant barrier to attending.

Participants wanted to learn a variety of things from the course but in particular information about diet – what food they can and cannot eat and in what quantities - and seven people requested the same content as the DESMOND course, seven wanted information on how to manage their condition and seven, including six HAREF participants wanted information on how and where to exercise. One D/deaf participant felt strongly that the course should focus on imparting facts and not the sharing of attendees' experiences as this resulted in the session they attended running over and their interpreters having to leave before all the information had been given out.

Seventeen people (34.7%) however requested changes to this course, either by including aspects of the other courses or suggesting new things to include:

- Online information to support the course from a trusted source that they could refer back to x4
- Session times to mirror DESMOND x3
- Longer sessions
- 10 sessions, an hour in length
- Hospital setting x2
- Held at Deaflink
- Better management of attendees
- Smaller group size
- Follow-ups x2

- BSL interpreters available x2
- Information in Plain English and visual accompaniments e.g. Illustrating changes in the thickness of blood by showing water on its own and water with different concentrations of sugar in it, going through a straw.
- Include a cookery session
- Give the same information in different formats to reinforce the message

Two-thirds of people expected information to support them once the course was finished mostly in the form of leaflets, access to a helpline or manual.

3.10.4.2Option 1

By far the most frequently mentioned reason (23, 69.7% of participants) for choosing Option 1 was the longer sessions over a shorter period which got it over and done with. Also seven people (20.6%) had been on the DESMOND course before and felt it worked well for them. Five people (14.7%) preferred a hospital location. They mostly wanted to learn about diet and the effects of the condition.

Fifteen people however requested changes to this course, either by including aspects of the other courses or suggesting new things to include:

- Online information to support the course from a trusted source that they could refer back to x3
- More flexible times x3
- Community setting x3
- At home
- Include information about statins and diabetes
- More detailed information
- Clarification about high vs low carbohydrates diets
- Time to ask questions
- Remove the round robin introductions
- Larger room size
- Longer course
- More flexible times
- Different course leaders

Again the vast majority of people (97.1%) expected information to support them once the course was finished mostly in the form of leaflets.

3.10.4.3Option 3

Nine people (9.6%) chose the computer-based option. The reasons given for choosing the computer option were that people could do it in their own time, they can do it at home and on their own, it is shorter than the other options and they can review the information and take time to understand it. They wanted to learn about diet mainly. One person requested a change to the course to include more tailored information.

People requested a booklet, online information or access to a helpline and the chance to meet other diabetes patients.

3.10.5 Preferences of education courses generally

In addition to being asked their views around specific course formats, participants were also asked generally what their preferences were for a course location, leader, group type, time and duration.

Over half of people (53, 56.4%) requested a community location due mainly to convenience and feeling uncomfortable in a hospital setting and for HAREF participants, the reach of the course, as family members and friends and other people with the condition may be able to attend. One fifth of people (20.2%) had no preference of location. Everyone was happy to have sessions run by nurses or healthcare workers who were knowledgeable about the condition but one D/deaf person requested that they also had deaf awareness training and training materials to reflect that.

In terms of group types, 76.6% (72 people) had no preference. However, all six HAREF participants felt that having community-based groups was important so that family members and friends could also attend, four people asked for groups by age and three by similar blood glucose score, two people requested a group with other D/deaf people and one requested a single gender group. In terms of times and days, 28.7% of people (27) had no preference, the main times for others were daytime or mornings and weekdays. For the duration of the course and in contrast to the overall preference for Option 2, more people (41, 43.6%) requested longer but fewer sessions compared to 35 (37.2%) who wanted shorter but more sessions. Sixteen people (17.0%) had no preference. Twenty-two people (23.4%) suggested other ways to receive the information with six requesting a website to complement the course. Amongst other things emails, practice staff and leaflets were also mentioned.

3.10.6 Barriers to attending a course

Participants were asked whether anything would prevent them from attending a course. One third of people (33, 35.5%) felt that nothing would prevent them. For the remaining people the main reasons were the timing of the course, illness, accessibility issues or work commitments. In terms of accessibility issues, eight people (8.6%) highlighted not having the course provided in another language or having no spoken language support or an interpreter available, not being physically able to access the building due to a mobility chair and for the participant who was DeafBlind they would need a minimum of double the usual time for communication with a manual interpreter so felt that attending a course was not an option for them.

3.10.7 Encouraging people to attend a course

Fifty-eight people (61.7%) suggested ways to encourage people to attend a course in the future. The main suggestion, mentioned by 22.4% of people (13) was to stress the seriousness of the condition within the letter or during discussions with practice staff.

Nine people (15.5%) felt that the benefits of the course needed more emphasis, six HAREF participants (10.3%) felt that proactively telling patients that there would be language support available would encourage black and minority ethnic communities to attend a course, five people suggested having the course endorsed by previous attendees and four suggested emphasising the fact that you can recover or get better.

3.10.8 Other comments

A number of people commented that they were looking forward to attending the DESMOND course, one participant requested a more personalised dietician session which took into account their other conditions and one requested a print out of their blood test results. Four people requested things around prevention that the health service could do; one wanted testing kits to be distributed to people to test themselves, one felt they should have been warned by their GP that they were at risk of developing the condition and two people who had been borderline for a length of time felt that they should have been offered a course around prevention.

Section 4: Recommendations

4.0 Recommendations

It is suggested that NHS Newcastle West CCG and NHS North and East CCG take time to analyse the findings of this research to inform the decision on the future service delivery model for diabetes education. However, from the findings, some recommendations can be made.

4.1 Key recommendation

4.1.1 Recommendation 1: Preferred option
In terms of participants' preference for an education course, 49 people (52.1%) stated that they would choose option 2 if they were to attend in the future compared to 34 people (36.2%) who would choose option 1 and nine people (9.6%) who would choose option 3.

It is recommended that:

- If only one course format can be offered to patients in the future, consider providing option 2. However it must be noted that in terms of option 3, the cohort of people we spoke to was older people; we did not speak to anyone 34 or under and nearly two-thirds were 65 and older. Therefore, this option may have been more preferable to a younger age group.

4.2 Diagnosis

4.2.1 Recommendation 2: Diagnosis information
Thirty-two people (34.0%) suggested information they would have liked to receive at their diagnosis to enable them to start making immediate changes to their lifestyle and five people had difficulties accessing the information.

It is recommended that:

- Patients receive some more detailed information they can take away from the consultation around diet so that they can start to make changes straightaway before seeing a dietician or going on a course. This should include the best foods to eat and cut out, how to understand food labelling and some example recipes taking into account the sorts of food that people cook across communities. This information should be appropriate to the patient taking into account their level of English and any disabilities they may have.

4.3 Education courses

4.3.1 Recommendation 3: Accessing the course
One D/deaf participant had to wait eight months to get onto the course due to interpreter booking/fee issues.

It is recommended that:

- The appointment system for booking onto a course is flexible enough to take into account people who may need extra support to attend, ensuring that there are no delays for anyone accessing the course.

4.3.2 Recommendation 4: Course accessibility

Several participants requested access to BSL interpreters, spoken language support and information provided in Plain English with visuals. One participant felt that the course leaders should also have deaf awareness training.

It is recommended that:

- Any course takes into account the accessibility needs of all patients to ensure that everyone can attend a diabetes course if they wish

4.3.3 Recommendation 5: Course management

One D/deaf participant felt strongly that the course should focus on imparting facts and not the sharing of attendees' experiences as this resulted in the session they attended running over and their interpreters having to leave before all the information had been given out.

It is recommended that:

- Sessions are strictly managed in terms of timings to ensure that all attendees have the opportunity to gather all of the information on offer.

4.3.4 Recommendation 6: Course location

Participants were asked generally what their preferences would be for a course location 53 people (56.4%) requested a community location compared to 18 people (20.5%) who would prefer a hospital based course and 19 people (21.6%) had no preference.

It is recommended that:

- Courses be offered at community locations.

4.3.5 Recommendation 7: Course times

Participants were asked generally what their preferences would be for course times. Twenty-five people (26.6%) would be happy to attend a course during the daytime, 14 (14.9%) would prefer mornings, 11 (11.7%) afternoons and weekdays were requested by eight people (8.5%). In addition, when asked about barriers to attending a course, the timing of it was an issue for 10 people (10.6%) and others said it would depend on other personal or work commitments.

It is recommended that:

- Patients are offered a selection of course times, either during the mornings, afternoons or evenings to enable them to attend a course.

4.3.6 Recommendation 8: Course duration

Participants were asked generally what their preferences would be for the course duration. In contrast to the preference for Option 2, people would prefer longer but fewer sessions. Forty-one people (43.6%) requested this option compared to 35 (37.2%) who would prefer shorter sessions over a longer period although it must be noted that the difference in numbers is marginal.

It is recommended that:

- Consideration is given to the optimum duration of the course and length of session times. It is suggested however that session times should possibly not be as long as three hours or if this length of time is chosen, ensure that there is a break and refreshments available for attendees.

4.3.7 Recommendation 9: Course content

Participants were asked what they would like to learn from a diabetes education course. Numerous suggestions were made but those mentioned by at least ten percent of people were mainly around diet (40 people, 50.0%) followed by how to manage the condition (10 people, 12.5%) the same information as was given on the DESMOND course (nine people, 11.3%) and how and where to exercise (11.3%).

It is recommended that:

- The course content is examined and if deemed necessary, some additional information be provided around diet, management of the condition and appropriate exercises to do and where to go to do them. In particular, what foods they can and cannot eat and in what quantities, food labelling and the glycaemic index, again taking into account the sorts of food that people cook across communities.

4.3.8 Recommendation 10: Support once the course had ended

Thirty-six people (38.3%) requested leaflets, 12 people (13.8%) requested a manual, 11 people (11.7%) requested access to a telephone helpline and 11 people (11.7%) requested follow-up sessions once the course had ended. In addition, 11 participants who had attended the DESMOND course requested additional support or information once the course was over in the form of follow-up sessions to check progress of attendees and top-up messages about diet changes and where to go to exercise. Six HAREF participants respondents requested that this follow-up take place within their community-based groups (where other family, friends or community members could attend) and within a year of attending the course. In contrast, none of the seven people who attended the LWTC which has ongoing support in the form of a buddy, requested any additional support.

One D/deaf participant asked about the availability of support groups and although there is one operating in the city, they were informed that there was no funding to help them access the group. Furthermore, when asked what changes participants would like to the course they had chosen, a further two people requested follow-ups and nine people requested online information to support the course from a trusted source that they could refer back to.

It is recommended that:

- Patients receive some form of support once the course is over but in particular consider providing:
    - Leaflets
    - A manual that they can work through or refer back to
    - A helpline
    - Some form of follow-up session provided about a year after attendees have completed the course to see how they are progressing and offer refresher information in a community setting.
    - The buddy system used by LWTC.
    - Support groups for attendees to access after the course or if this is not possible, ensure attendees are given up-to-date information about how to access groups in the community.
    - An online website to accompany the course and act as a reference point.

  If these suggestions are not viable ensure that attendees have, at the very least, a contact number to call in case they have any queries about the information they have learned on the course.

- Consideration is given to how those requiring extra support to attend a group are able to attend community-based support groups.

4.4 Encouraging people to attend the course

4.4.1 Recommendation 11: Methods of encouragement

Fifty-eight participants (61.7%) made suggestions about what might encourage people to attend an education course. Thirteen people (22.4%) felt that the seriousness of the condition needed more emphasis, nine people (15.5%) felt that the benefits of the course needed to be more clearly advertised and six HAREF participants (10.3%) felt that proactively informing people that language support will be available would also encourage people to attend.

It is recommended that:

- Any information about education courses emphasises the seriousness of the condition and in particular how not managing diabetes can lead to deterioration of eye sight and feet problems. The benefits of the course should also be emphasised more clearly as should the availability of language support.

4.5 Prevention

4.5.1 Recommendation 12: Preventing the disease

Four people (4.3%) made suggestions around preventing the disease – distributing testing kits to patients, informing patients in advance that they made be at risk of diabetes and offering borderline patients the opportunity to attend a course around prevention.

It is recommended that:

- Although only four people had issues around prevention it is felt that any actions around this would have a noticeable impact on people developing diabetes in the city. Therefore, it is recommended that patients at risk of developing diabetes are offered the opportunity to attend a preventative course. If a course is not a feasible option, these patients should be given information about how to prevent themselves developing the condition.

Appendices

Appendix 1 - One-to-one interview/questionnaire questions

Ice breakers

1. Do you remember when you were diagnosed with diabetes?

2. Do you remember why you were diagnosed? E.g. you had symptoms you went to you GP with or it was picked up in a health check?

Initial information/education

3. When you were diagnosed, were you given any information?
   Yes – If yes, was this useful? What else would you have liked?
   No – If no, would this have helped? What type of information would you have liked?

4. After diagnosis were you offered any educational courses?
   Yes - If yes, what course? Did you attend? - Yes (go to Q5)
   - No (go to Q10)
   No – Go to Q12

Patient experience of current education courses

5. Do you remember how you were referred to the course?

6. Where did you access it?

7. What were your expectations from the programme?

8. Where these met?
   If no, why not?
   If yes, why?

9. Did you get any ongoing support after the course had ended? E.g. booklet, information (then go to Q12)
   Yes – If yes, was it useful? What else would you have liked?
   No – If no, would you have liked this?

10. Why did you choose not to attend the course?

11. If you were offered the opportunity to attend an education course in the future, what would encourage you to do so? (E.g. more appropriate times or locations)

Self-management

12. What do you do to self-manage your condition?

13. If you don’t do anything to self-manage your condition, what information would help you?

14. Are you and your condition supported by anybody at home e.g. friends/family/carers?
    If so, what would help them to support you?

Testing the menu

Currently, **newly diagnosed patients** are invited to attend some education sessions around living with diabetes and things you can do to improve your health related to diabetes.

I am now going to show you some ideas about different ways of educating people about diabetes, and if you were to attend, which option would suit you best.

15. Which of these options would you prefer to attend and why?
    If “none”, go to Q25

16. What would you want to learn from this course?

17. Would you expect to be given information to support you after the course?
    Yes
    No
    If yes, what information would you like? (E.g. leaflet, manual, helpline etc.)

18. Are there any aspects of the course you picked that you would change?
    If yes why?

19. Are there any aspects of the other course(s) that you think would be good to include?
    If yes, which and why?

Details – place, time, length, composition

20. Where would you prefer to go to attend a diabetes course – a Hospital or Community location and why?

21. These sessions would be led by a nurse or a healthcare worker, how would you feel about this?

22. If your course did involve attending group sessions, would you prefer any specific group types? (E.g. single gender, age or lifestyle related)

23. What days and times are best for you to be able to attend sessions?

24. Would you prefer more but shorter sessions or longer but fewer sessions? E.g. two four-hour sessions or six two-hour sessions?

25. What would prevent you from attending a course? E.g. certain days, times, lack of information

26. Do you have any ideas that would encourage people to attend a course?

27. How else might you like to receive the education?

28. Any other comments?

Monitoring

29. Gender

Male	☐	Female	☐

30. Age

Under 18	☐	55 – 64	☐
18 – 24	☐	65 – 74	☐
25 – 34	☐	75 – 84	☐
35 – 44	☐	85 and over	☐
45 – 54	☐		

31. How do you describe your sexuality?

Lesbian	☐	Bisexual	☐
Gay	☐	Prefer not to answer	☐
Heterosexual	☐		

32. Please indicate your ethnic background:

White	✓	**Asian or Asian British**	✓
British		Indian	
Irish		Pakistani	
Central/Eastern European		Bangladeshi	
Any other White background		Any other Asian background	
Mixed		**Black or Black British**	
White and Black Caribbean		Caribbean	
White and Black African		African	
White and Asian		Any other Black background	
Any other mixed background			
Other ethnic groups			
Chinese			
Any other ethnic group (*write in*) ……………………………………………………………………………………………			

33. Do you consider yourself to have a disability?

Yes	☐	No	☐

34. What is the first part your postcode?

_ _ _ _

Appendix 2 – Focus group schedule

1. Do you remember how you found out that you have diabetes?

2. How did you feel?

3. What did you want to know?

4. Did you get the information you needed?

5. Did you understand all of the information?

6. Did you have any follow-up questions?

6a. If yes – what were those questions?

7. Did anyone offer you a course on diabetes?

7a. If yes, and you went on the course:

- Did you go on it?
- Tell me about it (your experience of it, including how easy it was to get to it; and what you learned)
- What information and/or support did you need afterwards?

7b. If yes and you didn't go on the course:

- Why didn't you go on it? (barriers e.g. venue, timing, support needs incl. language support)
- What information and/or support do you think you might need afterwards?

8. Here are some ideas about ways of educating people about diabetes so they can look after themselves with the help of professionals – what do you think?

- Diabetes Centre venue; 2 x 3hour sessions one week apart during daytime; approx. 10 in group with each person able to bring a family member; information pack to take home
- Community venue; more shorter sessions - 6 x 2hr to 2.5hr sessions; day-time, evenings and weekends; language support as needed
- Computer-based

9. How else might you like to receive the education?

10. What would help you take part in a course?

11. What might stop you taking part in a course?

12. What information and support do you think your family needs?

Appendix 3 – Combined participant profile

Gender

	No. of participants	% of participants
Male	45	47.9
Female	48	51.1
No response	1	1.1
Total	94	100.0

Age

	No. of participants	% of participants
18-24	0	0.0
25-34	0	0.0
35-44	4	4.3
45-54	7	7.4
55-64	23	24.5
65-74	34	36.2
75-84	21	22.3
85 and over	5	5.3
Total	94	100.0

Location – first part of postcode

	No. of participants	% of participants
NE1	1	1.1
NE2	3	3.2
NE3	30	31.9
NE4	12	12.8
NE5	14	14.9
NE6	17	18.1
NE7	9	9.6
NE13	3	3.2
NE15	3	3.2
NE28	1	1.1
No answer	1	1.1
Total	94	100.0

Ethnic background

	No. of participants	% of participants
White British	79	84.0
White Irish	0	0.0
Central/Eastern European	1	1.1
Any other White background	1	1.1
Mixed White and Black Caribbean	0	0.0
Mixed White and Black African	0	0.0
Mixed White and Asian	2	2.1
Any other Mixed background	0	0.0
Asian or Asian British - Indian	3	3.2
Asian or Asian British - Pakistani	4	4.3
Asian or Asian British - Bangladeshi	1	1.1
Any other Asian background	0	0.0
Black or Black British – Caribbean	0	0.0
Black or Black British - African	3	3.2
Any other Black background	0	0.0
Chinese	0	0.0
Any other ethnic group	0	0.0
Total	94	100

Sexuality

	No. of participants	% of participants
Bisexual	0	0.0
Gay	0	0.0
Heterosexual	84	89.4
Lesbian	1	1.1
Prefer not to say	9	9.6
Total	94	100.0

Do you consider yourself to have a disability?

	No. of participants	% of participants
Yes	24	25.5
No	64	68.1
Prefer not to answer	6	6.4
Total	94	100.0

Appendix 4 – INE participant profile

Gender

	No. of participants	% of participants
Male	44	52.4
Female	40	47.6
Total	84	100.0

Age

	No. of participants	% of participants
18-24	0	0.0
25-34	0	0.0
35-44	3	3.6
45-54	6	7.1
55-64	23	27.4
65-74	28	33.3
74-84	19	22.6
85 and over	5	6.0
Total	84	100.0

Location – first part of postcode

	No. of participants	% of participants
NE1	1	1.2
NE2	3	3.6
NE3	29	34.5
NE4	6	7.1
NE5	14	16.7
NE6	16	19.0
NE7	8	9.5
NE13	3	3.6
NE15	3	3.6
NE28	1	1.2
Total	84	100.0

Ethnic background

	No. of participants	% of participants
White British	75	89.3
White Irish	0	0.0
Central/Eastern European	1	1.2
Any other White background	1	1.2
Mixed White and Black Caribbean	0	0.0
Mixed White and Black African	0	0.0
Mixed White and Asian	2	2.4
Any other Mixed background	0	0.0
Asian or Asian British - Indian	1	1.2
Asian or Asian British - Pakistani	1	1.2
Asian or Asian British - Bangladeshi	0	0.0
Any other Asian background	0	0.0
Black or Black British – Caribbean	0	0.0
Black or Black British - African	3	3.6
Any other Black background	0	0.0
Chinese	0	0.0
Any other ethnic group	0	0.0
Total	84	100.0

Sexuality

	No. of participants	% of participants
Bisexual	0	0.0
Gay	0	0.0
Heterosexual	82	97.6
Lesbian	0	0.0
Prefer not to answer	2	2.4
Total	84	100.0

Do you consider yourself to have a disability?

	No. of participants	% of participants
Yes	20	23.8
No	64	76.2
Total	84	100.0

Appendix 5 – HAREF participant profile

Gender

	No. of participants	% of participants
Male	0	0.0
Female	6	100.0
Total	6	100.0

Age

	No. of participants	% of participants
18-24	0	0.0
25-34	0	0.0
35-44	1	16.7
45-54	0	0.0
55-64	0	0.0
65-74	4	66.7
75-84	1	16.7
85 and over	0	0.0
Total	6	100.0

Location – first part of postcode

	No. of participants	% of participants
NE4	6	100.0
Total	6	100.0

Ethnic background

	No. of participants	% of participants
White British	0	0.0
White Irish	0	0.0
Central/Eastern European	0	0.0
Any other White background	0	0.0
Mixed White and Black Caribbean	0	0.0
Mixed White and Black African	0	0.0
Mixed White and Asian	0	0.0
Any other Mixed background	0	0.0
Asian or Asian British - Indian	2	33.3
Asian or Asian British - Pakistani	3	50.0
Asian or Asian British - Bangladeshi	1	16.7
Any other Asian background	0	0.0
Black or Black British – Caribbean	0	0.0
Black or Black British - African	0	0.0
Any other Black background	0	0.0
Chinese	0	0.0
Any other ethnic group	0	0.0
Total	6	100.0

Sexuality

	No. of participants	% of participants
Bisexual	0	0.0
Gay	0	0.0
Heterosexual	0	0.0
Lesbian	0	0.0
Prefer not to say	6	100.0
Total	6	100.0

Do you consider yourself to have a disability?

	No. of participants	% of participants
Yes	0	0.0
No	0	0.0
Prefer not to answer	6	100.0
Total	6	100.0

Appendix 6 – Deaflink participant profile

We have not included the personal profiles of the respondents in this report due to the low number of contributors and confidentiality.

Appendix 7 – Deaflink report

DIABETES EDUCATION AND DEAF ACCESS

Deaflink Responses

Heidi Jobling
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Deaflink Diabetes Education summary

August 2014

Methodology

Deaflink invited feedback from our members 3 weeks through July and August. We conducted one to one interviews and also made the questionnaires available through our website.

We had 4 responses (2 D/deaf, 1 hard of hearing and 1 deafblind). All respondents were either living in Newcastle.

We spoke to a further 12 people but they were not in the target group - it was difficult to find members who had been diagnosed in last 5 years.

Summary of Findings

The low number of responses makes it difficult to draw any strong conclusions nevertheless there are some interesting correlations and conflicts

All respondents were diagnosed through routine blood or general health checks.

Only 50% were offered a course. We have no information about whether the other 50% felt that they would have liked to attend a course if it had been offered.

With regard to what the attendees wanted from their course there were common areas – information; advice and answers to questions. There were 2 opposing views of a] peer support and opportunities to share experiences and b] want the facts not chat!

"My experience of the two sessions were people wanting to share their experiences, not that there is anything wrong with that, but I came to learn facts not to hear how someone finds it difficult to eat because of children or how good someone has lost so much weight since diagnosed".

"More explain, personal experiences from others to share, more experiences and more simple information"

"And to meet with other Type 2 diabetics and how they cope".

Due to need for interpreters some BSL users felt this had led to unnecessary delays in their attendance at the course and options offered. One person felt that the delays were discrimination.

"No interpreter in this check-up. Then nurse said have to go back to higher diabetic nurse and she realised need to book an interpreter then went back the next week and told got type 2 diabetes. Was upset and got information how eat well without sugars?"

"With great difficulty!!!! Problems over interpreter bookings/fees delayed my attendance. Once on course everyone was referred to course within 6 weeks whereby I finally attended 8 months later".

Some also expressed concerns about accessible information and support. There is a support group but have no funds for BSL interpreter.

“Searched online but was confused due to personal restrictions of food and foods to avoid/eat according to diabetes. Contacted Diabetes UK, said don't work with deaf people and referred me to Action on Hearing Loss who subsequently said don't do diabetes! “

“Lectures and questions were very good but most people disappointed because no follow up. One can only take so much new information and especially when elderly (60+ years)”.

Half expressed that they would like more support and opportunities to learn. They would have liked the opportunity to follow up with the same group – share what they had learned. They felt the issue of family attitudes, social eating and the guilt of their diabetes affecting family was an area that they could benefit from exploring further.

“WHAT TO EAT and cope with social eating.”

“They find it difficult to help because they don't understand the eating pattern 'you can have a little' or 'I know diabetics who eat this' 'well I won’t have any then' and you feel guilty”.

2 out of the 4 respondents said that community based sessions that were shorter but more of them would help. None of them had issues with a nurse or other healthcare worker delivering the sessions as long as they were trained and had relevant experience. They did however feel strongly that their disability – deafness should be addressed and planned in the delivery e.g. better planned breaks, clearer more visual information, BSL interpreters and much longer sessions with other D/deaf people would be their preferred way to learn about their Diabetes. One person preferred the computer app as it would help them learn better at their own pace. The person who was Deafblind felt that none of those options were appropriate as they would need much more specialist support.

In conclusion, some people have had a relatively positive experience and some had negative experience, some want to share experiences and some don’t – one size does not fit all.

DIAGNOSIS

1 Do you remember when you were diagnosed with diabetes?

3 were within last 12 months and one was in November 2011

2 Do you remember why you were diagnosed?

3 were diagnosed because of routine blood checks (annually or quarterly.
1 said they were diagnosed "When went for a GP check up in a nurse clinic like MOT, weight and urine sample".

INFORMATION AND EDUCATION AT THE BEGINNING

3 When you were diagnosed, were you given any information?

All respondents were given information – a leaflet or the nurse tried to explain.

"Nurse asked how are you? Said ok but really poor eating. Blood sample and checked weight. No interpreter in this check-up. Then nurse said have to go back to higher diabetic nurse and she realised need to book an interpreter then went back the next week and told got type 2 diabetes. Was upset and got information how eat well without sugars? Another appointment and the nurse booked an interpreter and we went back and more questions about food and leaflet. Need eye test check-up at general hospital? Wife have to contact Newcastle Communication Support to tell who want preferred interpreters."

3a If yes, was it useful? What else would you have liked?

"More advice on food and a means of measuring my blood sugar. One has no idea what is happening".

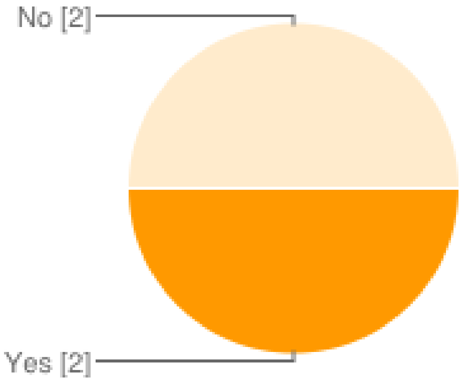
"Simple information about food with pictures, some words hard to understand and I have to ask what they meant. Some words ok understand. Nurse said same food as normal but without sugar. Five fruits a day, amount of each fruits in one day. Interpreter was there".

"The leaflet was okay but hard to ask about the information and what words means as nurse not available all the time. First time visit to clinic 7 months after diagnosed. For another check-up as well MOT weight".

To know more about the implications!

Searched online but was confused due to personal restrictions of food and foods to avoid/eat according to diabetes. Contacted Diabetes UK, said don't work with deaf people and referred me to Action on Hearing Loss who subsequently said don't do diabetes!

4 After diagnosis were you offered any educational courses?



4a Did you attend the course offered?

Both people offered the course attended.

EXPERIENCE OF EDUCATION COURSE

5 Do you remember how you were referred to the diabetes course?

“from the practice nurse”

“With great difficulty!!!! Problems over interpreter bookings/fees delayed my attendance. Once on course everyone was referred to course within 6 weeks whereby I finally attended 8 months later”.

6 Where did you go for the course?

- Brunton Park
- General Hospital and GP practice at Brunton Park

7 What did you hope to get from the course?

“Why did I have Type 2 diabetes? How should I change my life style? WHAT TO EAT and cope with social eating.”

“Clearer understanding of limitations of food types. Understanding of diabetes type 2. Possible peer connection network group. Opportunity to ask questions on overcoming barriers”

8 Did you get this/these from the course?

There were mixed feelings in answer to this question. Both respondents replied Yes and No.

“Yes and No. Learnt there is a group that meet but no funding for deaf to access. They have speakers which supplies information. Anger at being left for so long to attend course compared to hearing. Got more understanding of diabetes but by this time had lost interest and couldn't careless what happens after realising the discrimination and lack of respect. “

“no - more psychological help needed. yes - Lectures and questions were very good but most people disappointed because no follow up. One can only take so much new information and especially when elderly (60+ years)”.

9 Did you get any ongoing support after the course had ended? e.g. Booklet

Half were offered further support.

9a If yes, was it useful? What else would you have liked?

A follow up meeting as the diabetic nurses were very good. Men especially found all the food information confusing. And to meet with other Type 2 diabetics and how they cope.

9b If No, would you have like more support? What?

Nutritional support regular check up with nurse every month/months.

No respondent was offered the course but did not attend.

SELF MANAGEMENT

What do you do to self-manage your condition?

Again mixed replies to this question, ranging from demotivated to medicated and monitoring closely.

- No motivation as I’m isolated. No one else to share experience deaf or hearing
- A bit more aware of what I eat and drink

- I manage with difficulty. I have to keep saying 'no' to food and 'I am a diabetic' e.g. no sugar and much less carbohydrates.
- Box of pills from the chemist and monitors all food intake.

If you don't do anything to self manage your condition, what information would help you?

- I would like some more formal information, related specifically to me and my circumstances (DeafBlind)
- Hard to say what information would help as not aware and only diabetes happened for 10 months.
- Nutritional support and regular check ups, contact person to seek support.

Are you and your diabetes helped by anyone at home?

Half of the respondents said they were helped at home.

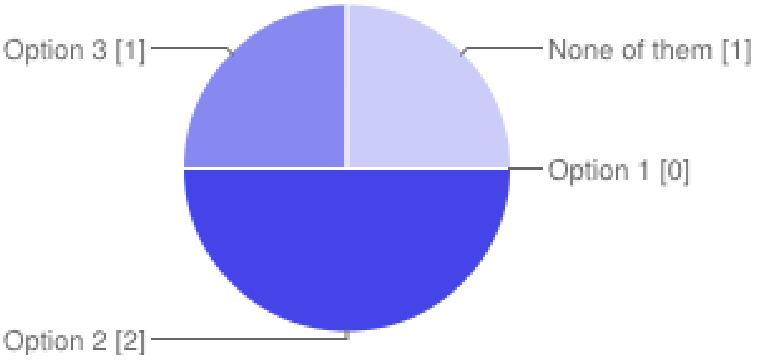
If yes, what would help them support you?

“Keep an eye on me, bath, and put socks on as can't reach feet. Feed and give tablets at right time in morning, afternoon and night. Get shopping and papers”.

“They find it difficult to help because they don't understand the eating pattern 'you can have a little' or 'I know diabetics who eat this' 'well I won’t have any then' and you feel guilty”.

TESTING THE MENU (FUTURE OPTIONS)

Which of these options would you prefer?



Why do you prefer that option?

- I have done the Desmond course but I would like to do it again, if possible - Option 2.

- Brain freezes after a while! Three sessions gives chance to think things through and bring to next session. If in local community centre, chances are people attending live nearby and potential for peer support

- When learning in a course via BSL, easy forget after the course and prefer on the computer so can read again and again repeat but want BSL on the computer to understand diabetes information better. I have a computer at home.

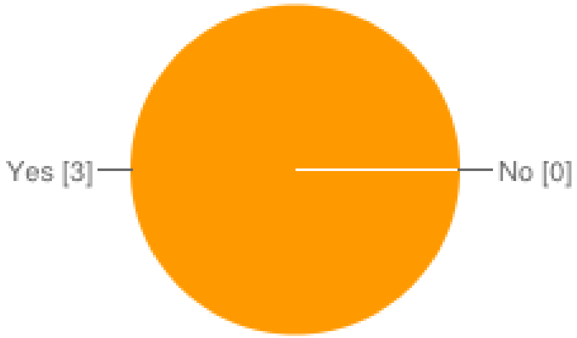
What would you want to learn from this course?

- Food, how manage diabetes, drinks, how much portion can eat, places to go, exercise like chair exercise
- Facts. My experience of the two sessions were people wanting to share their experiences, not that there is anything wrong with that, but I came to learn facts not to

hear how someone finds it difficult to eat because of children or how good someone has lost so much weight since diagnosed. Therefore the facilitator had to rush and omit certain parts of course and over ran but interpreters only booked for 3hrs and had to leave before facilitator had completed their list.

- How to cope with food and how much and what sugar (fruit) carbohydrates I can have.

Would you expect to be given information to support you after the course?



If yes - what would you like? Leaflet? Manual? Helpline?

- Website and leaflet
- Contact groups, "helpline" that was accessible.
- Manual, Helpline and meetings with other Type 2 diabetics

Are there any parts of the course you picked that you would change? If yes, what would you change and why?

BSL interpreter/clips on the course and easier to understand because of English, want simple plain English. Want visual pictures and photos to understand better.
More sessions, less people in group. Too many in small room made it uncomfortable when you also have to account for space for interpreters

Are there any parts of the other options that you thought would be good to include? If yes what and why?

“Follow up support through online would be helpful”
“Like to have the course through the day at Deaflink - easier for me and BSL and easier access to get to Deaflink.”

DETAILS

Where would you prefer to go to attend a diabetes course?

2 people replied to this and both wanted to attend at a Community Building

Why?

Easier for me and BSL, Easier to get to.

The course would be led by a nurse or a healthcare worker, how do you feel about this?

“Fine and nurse more experienced because know about diabetes and from clinic at general hospital”
“I would be delighted especially if they have diabetic experience”
“As long as nurse has deaf awareness training and training materials to reflect that!! i.e. telephone numbers!”

If the course involved you coming to group sessions, would you prefer a specific group?

One person said ‘Any type’ and 2 replied that they would prefer sessions with other deaf people.

In terms of time of the week – 3 respondents did not reply indicating that they did not have any preference. The one respondent who did reply felt late morning on Monday, Thursdays and Fridays would best suit them.

Would you prefer

More sessions but shorter (e.g. 4 x 2 hour)	**3**
Fewer sessions but longer (e.g. 2 x 4 hour)	**0**

What would you prevent you from attending a course?

- “Ignorant/patronising nurses! Need outline of each session sent out prior to course beginning so everyone knows when a certain fact will be discussed. Experienced nurse's phrase was "we will be talking about that later" repeatedly!”
- “Depends on can't be bothered to go, confidence and how well I am on the day. hard to say. Also if no interpreter or BSL”.
- “I am totally Deaf and Blind, I rely on a deafblind manual interpreter. I need a minimum of double the usual time for communication. I would not be able to join in group sessions”.

Do you have any idea's that would encourage people to attend a diabetes course?

“Current Course not suitable. I would need 1 to 1 advice, information and support”.
“More explain, personal experiences from others to share, more experiences and more simple information because hard for deaf people to understand what that mean. I learn a lot from deaf and hearing friends who are diabetic but one friend died”.
“Sorry - some people just bury their heads in the sand”.
“Open course up to another person in that person's life i.e. parent/Sibling/friend/partner as lots of information to take in is too much for one to remember. Supportive person can support accurately and appropriately due to attending course”.

Any other comments?

- I would like to help with any trials to tackle Type 2 diabetes. I would like to be able to measure my blood sugar and know how my body is coping with my diet.
- I would like to learn more about diabetes in the future, family members have diabetes.
- I had a negative experience whereas others may have had positive experiences. Such as on course everyone had had their eye examination within those 6 weeks, I had not. Being a deaf person, eyes are more precious!!

We have not included the personal profiles of the respondents in this report due to the low number of contributors and confidentiality.

Appendix 8 – HAREF report

Diabetes education:

Experiences of people in black and minority ethnic communities

60 people, 55 women and 5 men, from minority ethnic communities in Newcastle took part in discussions about diabetes education facilitated by HAREF. Four of the discussions involved people within family groups.

Language support was needed in nine of eleven separate discussions, for at least one person taking part. This support was provided by bilingual workers and, in family groups, by bilingual relatives.

Just over half (33) of the people who took part in discussions have been diagnosed with type 2 diabetes, 6 within the last five years.

Of those who have been living longer term with diabetes, 6 were diagnosed between five and ten years ago, 14 between ten and twenty years ago, 6 between twenty and thirty years ago, and 1 thirty-five years ago.

6 of the women who took part are from the Chinese community, 10 from the Indian community, 12 from the Bangladeshi community, and 27 from the Pakistani community. 3 men from the Bangladeshi community and 2 men from the Chinese community participated.

The age range of participants was: 3 x 25-34; 4 aged 35-44; 4 aged 45-54; 14 aged 55-64; 29 aged 65-74; 6 aged 75-84.

48 participants live in the NE4 postcode area of Newcastle and the remaining 12 are spread across the city. One person currently living in Gateshead was resident in Newcastle at the time of their diabetes diagnosis. Another person, who lives in Newcastle, was diagnosed with diabetes while living in their country of origin.

A person from the Czech Republic was identified as having diabetes by their GP practice and invited by letter to take part in an interview. HAREF arranged language support for a telephone interview, at the beginning of which the person said that they did not think they have diabetes. This confusion illustrates the complexity of providing primary care support in the area of diagnosis of conditions where a lot of explanation and discussion is needed. Practices with a high number of people on their lists with English as a second language have highlighted the practical issue of managing appointments to meet need, in terms of time required for interpreter supported consultations.

People diagnosed with diabetes within the last five years

6 of the women who took part in discussions have been diagnosed within the last five years, one from the Bangladeshi community, two from the Indian community, and three from the Pakistani community. One of the women is aged between 35 and 44, four are in the 65-74 age range, and one is aged 75-84. All live in the NE4 area.

5 women remembered being identified through a health check. The younger woman had gestational diabetes during her pregnancies, and was subsequently monitored. She was identified as being at high risk of developing diabetes, which she initially controlled well through exercise and changes in diet. She was diagnosed with diabetes six months ago.

All of the women talked about the emotional challenge of getting a diagnosis of diabetes, illustrated by the following quotes from three of them:

“The diagnosis was a big shock. I had no symptoms and when I was told I had diabetes I felt depressed and frightened.”

"I never thought I would get diabetes because I eat healthy food and I walk around a lot. I thought I was just getting old. It is in my family and my husband has had diabetes for about 20 years so I already knew a lot about diabetes and what to do. My husband said he thought I might have diabetes and I went to the doctors and said that my husband had sent me. The doctor laughed and said he'd trust the test more than my husband. The test was positive. I tried managing it by changing my diet but I was already eating healthy food so there wasn't much scope and I felt very bad.”

“When I was first diagnosed I wondered how I would ever control it and it was scary”.

Three of the six women found it difficult to access any information because of their level of English skill.

The information that five women said they needed at the point of diagnosis was:

- how to take care of feet
- how to avoid infection
- what to eat and how to put that information in to practice with the food we cook
- where to go, including information about women-only space, to get in to the habit of exercising

One woman wanted support to make changes in her eating, as she felt she had “fallen in to the bad habit of snacking”.

All six women remember being referred to an education programme by their GP. Five of the women attended the Diabetes Centre Desmond education programme, and one is still taking part in the ‘Living well, taking control’ pilot programme facilitated by HealthWORKS. None of the women could remember having any particular expectations of the programmes to which they were referred.

The women who attended the Desmond programme at the Diabetes Centre could not remember any ongoing support. All highlighted the potential of follow-up sessions with their community-based groups, to top-up messages about how to make changes in diet and where to go to exercise.

The two women who attended the Desmond programme, whose level of English meant that there was no barrier to them getting the information, found it useful:

“I learned a lot of things I hadn't known about what to eat, and felt I got everything I needed at that point.”

"It was a very good programme because they explained everything very well.”

Two women who attended the Diabetes Centre education programme said that it was very difficult to understand the information because the session was long and the language was complicated. There was a language barrier for them.

The woman who is participating in the ‘Living well, taking control’ pilot programme, highlighted positive aspects of the support she is receiving:

“I was diagnosed 6 months ago. I had been controlling symptoms of pre-diabetes with diet and then everything I used to do wasn’t working. I was having ups and downs in my life and it felt like stress was catalysing everything. My GP looked at the whole picture and referred me to ‘Living well, taking control’ and I went to the first session in April. It’s at a familiar venue and that makes you want to go along. It’s a good approach with a lot of visual information. They help you to understand what happens to the thickness of your blood by showing different liquids, water on its own and water with different concentrations of sugar in it, going through a straw. That was such an eye-opener. Joining a group session has had an immediate impact (HbA1c had dropped at last reading from 63 to 36). The group has been really useful for stress control and for recognising a range of symptoms that other people were describing, because I had been thinking I was going mad. It was so helpful to hear people talking about anxiety and I could think to myself “It’s not just me. It does happen to other people”. Someone said they felt as though their head was exploding and I recognised that. It was like a picture coming together. It made sense and it was reassuring. It was interesting listening to people from other cultures and hearing about different foods. There is a lot of home cooking in south Asian communities and so people don’t always know how to work out what’s in the food - there might not be any label. The healthy eating cooking sessions are very good because I’ve picked up things like using fromage frais and low fat yoghurt. For me, being with people and sharing ideas really helps. There’s a group atmosphere. And there’s a feel good factor in offering support to others in the group. You go away feeling better. The HealthWORKS professionals are bringing information to you that’s hard to find, and what they tell you is accurate and up-to-date. You get all of the information and there’s support from your health buddy to make changes. It’s motivating. And once you get a few people aware, then the message goes around.”

Although three of the five women who attended the Desmond programme at the Diabetes Centre gave positive feedback, they agreed with the other three women that group sessions in familiar community venues are the best option:

“Bringing sessions out to places like here (venue of regular social group supported by the local authority) means it would get to people with a diagnosis of diabetes and their family members, as well as friends who might need to know things because there is diabetes within their families, or to be able to avoid developing diabetes. The group keeps on meeting after we’ve had the information, and people can encourage each other to exercise and eat different things and not eat as much.”

All six women highlighted the value of bilingual workers as language can be a significant barrier to the Desmond programme for some people. Three identified anxiety about getting to an unfamiliar place as a potential barrier to sessions in a hospital setting.

The five older women said that an online education programme would probably not be useful for their peers in south Asian communities, although younger family members might find it useful.