

## **Diabetes Care in Hounslow**

### **A REPORT ON THE FINDINGS OF FOCUS GROUPS HELD WITH HOUNSLOW CLINICAL COMMISSIONING GROUP DECEMBER 2013**

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#### **BACKGROUND**

Hounslow Clinical Commissioning Group are working with Diabetes UK to give local people with diabetes a chance to influence the diabetes services that they receive. In December 2013, 3 focus groups were held to explore people's general views of diabetes services and how they access them, and in particular their views on structured education programmes. Further information was also gathered through a Public Meeting between patients and CCG representatives, as well as a patient experience questionnaire. A telephone interview was also undertaken

This report presents the findings from these activities

#### **METHOD**

The focus groups were jointly hosted by Diabetes UK and Hounslow Clinical Commissioning Group, with Diabetes UK's Improving Local Services Together project team leading the facilitation and the note-taking. The groups were also supported by Fiona Thomas and Raquel Delgado from the CCG, and Olayinka Ayo from London Borough of Hounslow. Three key themes were addressed within the focus group, which each lasted around 2 hours:

- What do you think of the diabetes care that you currently receive (positive things and things that could be improved)?
- Do you generally feel that you are able to access services when you need to?
- What would encourage you to attend a diabetes education course?

On 9 December 2013 Hounslow CCG and Diabetes UK also jointly hosted a public meeting, where local patients were given a further opportunity to give their views of positive things about diabetes services, and things that could be improved.

A short patient survey has also been available for local patients to give their experiences of local care. Through the survey patients were asked about the 9 care processes and the frequency of checks, the ease of booking appointments with different services, personal care planning and views on the quality of different services.

A telephone interview was undertaken with a patient who was unable to attend the focus group sessions. The person was a new resident of Hounslow, and not yet accessing diabetes services. Therefore the interview focused on aspects of care that are important to them, and on structured education.

## PARTICIPANTS

The focus groups were advertised generally to all diabetes patients in Hounslow and were held in three areas that the CCG felt may be under-represented in terms of accessing services or putting their views forward. Attendance was as follows:

- Great West Road Locality, 4 December 2013 – 1 person attended
- Feltham Locality, 6 December 2013 – nobody attended
- Heart of Hounslow Locality, 14 December 2013 – 12 people attended

In all, there were 13 participants at the focus groups. 8 of the participants were male, and 5 were female. Overall attendance at the focus groups was disappointing. This was mainly due to a short amount of time available to recruit local service users, and the time of year potentially meant that people weren't able or willing to attend (in terms of weather and other commitments regarding the holidays). However due to the need to hold the sessions at this time in order to feed into the development of the Intermediate Care Service specification, this was an accepted risk.

There were 39 respondents to the patient survey.

## KEY THEMES

The below summarises the key themes arising from the focus group discussions and from the interview. Full details of the feedback from all focus groups and the interviews can be found as an appendix to this report:

### Positive things about care

The retinopathy programme was deemed to be very good by attendees of the focus groups. People felt that they received their checks (annually or more regularly if needed) when they were due them, and that the staff were very helpful – in terms of changing appointments and in explaining the results of screening and any complications

The care received at hospital was also deemed to be a key positive for the local area. People felt that the health professionals were knowledgeable about the condition and helpful in explaining things concerning their care. It was also commented, by a parent of a child with diabetes, that the paediatric nurse was very good and very responsive to their concerns and needs. Participants at the focus groups accessed services at different hospitals, but generally all were happy with the quality.

### Information and support provided by GP surgeries

Generally people felt that there should be more information available about diabetes through GP practices. This ranged from improving the literature available in waiting rooms (concerning diet, managing the condition and what diabetes is and complications that it can lead to), to advice given by health professionals themselves. People felt that more information should be provided to people on diagnosis to ensure that they understand the seriousness of the condition, and that time should be taken to make sure that people understand. This should be available in a variety of languages. One idea was that a booklet could be given to newly diagnosed patients, with advice about self-managing their condition – the patient could keep this and include test results and target levels to make it more personalised. It was also commented that the care planning process was not consultative enough, and not personalised to the needs of the individual.

In terms of leaflets and booklets in waiting areas, it was felt that there was not enough relating to diabetes available – certainly compared to other long-term conditions. Another element of this was that there was a feeling that GP's were unaware of programmes and services that patients can be referred to for further support, meaning some patients miss-out on these opportunities (such as structured education programmes).

A particular issue raised by a number of people was a lack of explanation from GP's concerning changes to medication – in terms of why the medication has changed, but also the effect that the new medication would have. Likewise, some participants commented that although they get their annual checks from their GP's the results are not always explained to them – for example one person said that they were told that their HbA1c level was too high, but were not given any advice on how to address it.

However, it should be pointed out that this wasn't the case with all participants. A number of people commented that they were happy with the service they received by their GP, that they got the care they feel they need and that they feel listened to. However the inconsistency in the level of support received from different surgeries was apparent.

### **Knowledge of diabetes issues by health professionals**

There was a general feeling amongst the focus group participants that there is a lack of knowledge of diabetes amongst health professionals, particularly those within GP surgeries. It was felt that in particular they did not understand Type 1 diabetes, or Type 2 for those using insulin. For this reason, participants felt that health professionals needed to be better educated on diabetes and the complications it can lead to, as much as patients. More specifically, the following areas were felt to be where knowledge and understanding could be improved:

- How insulin pumps work
- Rights of patients – for example, in the prescription of test strips and collections for sharp bins
- Spotting symptoms within children for early diagnosis, and links with other conditions
- Knowledge from locums when patients do not see their usual GP

### **Communication between services**

A number of people expressed frustrations with a lack of communication between the hospitals and GP surgeries. It was acknowledged that the IT systems between the two are not compatible, however it was felt that clinicians should be communicating better between themselves. This lack of communication has led to people receiving conflicting information and advice from different professionals, with others experiencing duplication in being told that they have to have blood tests undertaken with both services.

### **Access to services**

A number of issues were raised about being able to access services. Generally speaking, people seemed to be less concerned about where they went to receive care, as long as the professional they saw was knowledgeable, gave the patient enough time in their appointment and listened to them. A number of people mentioned that they would rather access services at the hospital than their GP surgery – reasons being because they are pleased with the service they receive at the hospital, it can be easier to arrange appointments. Similarly at diabetes clinics it was felt that you are given more time with the professional than at GP surgeries. Specific points made for specialist services included:

- Podiatry service is under-resourced and you can only access a podiatrist if you have a complication – it can be difficult to arrange an appointment
- There is a lack of availability of psychological and emotional support
- The area is under-resourced in terms of number of DSN's

In particular there were a number of points made about access to structured education programmes:

- A number of people were unaware that education programmes were available for people with diabetes – though would be interested in attending had they known
- Some people had attended the DAFNE education programme (which they thought was excellent) but had to go out of borough for it
- People need to have a greater choice of when they attend – including evenings and weekends
- Likewise, they should be held in a variety of venues to make it easier for people – libraries, leisure centres and mosques/other places of worship were mentioned as ways to help more people attend
- Information should be available on-line for those that aren't able to attend face-to-face sessions or would prefer self-learning

### **Content of Education Programmes**

There were some conflicting opinions of the X-PERT Education Programme. Attendees at the Public Meeting felt this was a key positive for the area and found it excellent and informative. However the majority of participants of the focus groups that had attended the course felt that the course was poor. This seemed to be particularly because not all had attended a course run by a health professional, with some courses being delivered by an X-PERT tutor. This meant that participants were unable to ask specific condition-related questions. Also, it was not relevant for all as it did not cater for people with Type 2 diabetes using insulin. It was also felt that more could be done to tailor courses for the audience (i.e. take into account cultural considerations regarding diet and cooking, and also provide information in large-print). Those that had attended the DAFNE course felt that the practical element, of needing to maintain a food diary as 'homework' was useful.

Generally people felt that being able to attend a face-to-face session to be valuable as they could ask questions about anything they were unclear of. However it was suggested that a web forum would be helpful for people to access for any questions they might have subsequent to attending the programme. People also felt that being part of a group with other people with diabetes was also very useful, as they could learn from each other as much as from the health professional delivering the programme.

### **ACTIONS TO BE TAKEN**

The findings of this work will be used to inform the development of the specification for the re-commissioning of Hounslow's Intermediate Diabetes Service.

The involvement activities carried out so far are the beginning of a process of working to improve how people with diabetes are involved in decisions about local care. A patient representative will be recruited to sit on the Hounslow CCG Diabetes Commissioning Group and a patient panel will be established to ensure the patient voice is involved in the whole of the commissioning process.

Findings will also be shared with each of the participants of the focus groups and telephone interviews, to let them know what action will be taken as a result of their involvement in the groups.

## APPENDIX

### Full notes from the Great West Road Locality, Ermine Centre on 4 December 2013

1 attendee - 1 female

#### Positives about care locally

- Generally I am happy with the care that I receive. I go to my GP Practice (in Feltham) for my annual checks, and see either the Dr or the Specialist Nurse.
- I have regular checks for my kidneys, though I have heard from other people with diabetes that they don't
- I get test strips on prescription

#### Things to be improved locally

- I've recently had a change to my medication (taken off of Metformin) but was told by letter, which didn't explain why. It also told me that I should up my insulin intake, but didn't tell me by how much. It would have been good to have a grid showing me the levels and how much (*the letter was shown to us, and was a letter between professionals which the patient was cc'd into – the language was quite technical and didn't say why the decision had been made*)
- I booked an appointment, but couldn't see my GP and so saw a stand-in – they didn't know about me and my care, and didn't know enough about the medication
- I think there should be more information available at GP surgeries for people with diabetes, particularly around diet, calorie content etc. And this should be available in large-print for those with visual impairments
- Communication between the specialist nurse at my GP practice, and the hospital should be better – I get mixed information from them

#### Access to services

- Because I have had some complications I have regular checks for my feet with a podiatrist (at Bath Road) and my eyes (at ASPH). These happen every 3 months and I am happy with them
- If I had the choice I would visit the hospital for all of my checks rather than my GP. Its easier to get an appointment, sometimes it can be dependant on the receptionist whether you're able to get an appointment at the GP
- I get to see a dietician regularly enough, but they don't give me much help – just tell me my diet is fine

#### Structured Education Programme

- I attended the XPERT education course, but it wasn't relevant for me. It was for Type 2 people on pills, but I am insulin dependant.
- I enjoyed being able to attend with other people with diabetes. I learnt a lot from the whole group not just those leading the course. But not everybody on the group stuck with it for all the sessions
- The timing (during the day) and location was good for me. I had a choice of venue and picked the one closer to me, and I was told the days it was held
- The group was offered to visit a supermarket but decided not to. Instead we were shown packages of food – but that, and the other information was no good for me as I couldn't see it. They need to provide more in large print

## Full notes from the table top discussions at the Public Meeting, Day's Inn Hotel Hounslow on 9 December 2013

### What is good about the current diabetes service?

#### Service provision

- Some patients have a positive experience with GP, including regular reminders for appointments, regular checks (podiatry services particularly good at Whitton, Chiswick Health Centre (→ referral to GP) and WMUH) and good access to DSN.
- Emergency care is readily available
- Health trainers are able to meet often
- Expert patient group was helpful – years ago provided weekly support in Hounslow

#### Management and treatment

- X-PERT patient education programme – this service is consistently reported as education and informative with regards to dietary advice and exercise tips. The meeting attracted many people who had completed the programme.

### What could be improved about the current service?

#### Service provision

- Delay between diagnosis and referral
- Care plans are not discussed/jointly agreed and do not address cultural barriers
- Care is not individualised and does not reflect each patient's personal goals
- Inconsistent service provision across GP surgeries – not all surgeries complete all checks
- Inconsistent advice and prescriptions on test strips (Type II) without dialogue or tests
- Results are simply given and their relevance not discussed
- Poor communication out of appointment
- Poor access to psychologist/emotional support
- Lack of co-ordination between specialist teams and too much repetition
- Long term patients are not offered the same services as newly diagnosed patients
- Not enough DSN (consistently “the most useful HCPs”)
- Patients are not educated on 15 Health Care Essentials
- No information is displayed in GP surgeries/by receptions
- Patients are not educated on the long-term complications at diagnosis – could improve compliance

#### Management and treatment

- Lack of dietary advice and tips on exercise
  - Suggestions: Increased access to DAFNE/DESMOND/X-PERT courses and dieticians, specialist advice on diets with insulin therapy, exercise regime prescription at diagnosis and increased education on the effects of drug therapy on requirements (e.g. long term Metformin use is linked to symptomatic B12 deficiency, specifically peripheral neuropathy, yet many patients are unaware of the need to supplement their diets)
- No information on other drug therapies and their side effects – “is Metformin the only option?”

Footcare

- Foot check generally consists of a basic sense test and does not take into account other early signs such as cramping
- Neuropathy – many patients do not understand the importance of this nor do they recognise the symptoms associated with this complication
- Podiatry services consistently quoted as under -resourced
  - Suggestion: one-stop shop for footcare

Volunteer group support

- Lack of support from consultants and GPs – they do not help to publicise support groups and fail to mention them to newly diagnosed patients even though many feel this is a vital to their knowledge of the condition and their ability to self-manage

## Full notes from the telephone interview on 12 December 2013

1 participant – 1 male (a new resident in Hounslow who currently receives services in Hammersmith and Fulham)

### Access to services

- I don't mind where I go to receive my care – the main thing is that whoever you see actually listens to you
- At the moment I go to a Diabetes Clinic (in Hammersmith and Fulham) for all of my checks apart from retinal screening, which is at the hospital. I rarely see the same doctor, which means that I don't have a personal relationship with the staff there. I've seen the Diabetes Nurse recently, for the first time in years
- Despite this, I'd rather go to a Diabetes Clinic for my appointments than to a GP, as I don't think you are given enough time in GP appointments
- Evening appointments would be much easier for me – and should be easier for the NHS to do than weekends

### Structured Education Programme

- I wasn't aware of diabetes education programmes being available in Hounslow until I heard at the public meeting on Monday. It is something I would be interested in. I did hear about something being offered in Hammersmith and Fulham, but you had to pay for it
- It would depend on when the sessions are held. For me, the evenings would be better – a start time of about 6/6:30 would be ideal.
- Mid-week sessions would be better for me, although I would consider a weekend programme
- I wouldn't mind travelling (within the borough) to get to a course. Although, going to Heart of Hounslow would be best location for me
- I would be willing to attend six sessions if needed to cover all of the information – but I would only want to do this mid-week in the evenings. I would be interested in a condensed version on one-day if it was held at the weekend. But its important to have a choice
- The opportunity to hear from others in a group setting sounds useful. I would prefer to hear the information face-to-face with a professional than by other means

## Full notes from the Heart of Hounslow Locality, held at Heart of Hounslow Centre for Health on 14 December 2013

12 attendees – 8 male, 4 female

### Positives about care locally

- The podiatry service (available in Whitton) is good
- ‘The fact that I moved house but was able to stay with the service at Queen Mary’s Hospital in Roehampton’
- The Retinopathy programme in Hounslow is very good – ‘I receive my annual check, and they are very helpful if you need to change your appointment. They also give you feedback and explain the results, and are quick to raise any concerns with you’
- ‘My GP Practice (Dr Mandel) is very good. They listen to me, and also provide me with enough test strips’
- The Paediatric diabetes nurse at West Middlesex Hospital is very good, very responsive
- ‘I’m pleased with the care I get at the hospital’
- Some members of the group commented that they received test strips (though not all said that they received enough)

### Things to be improved locally

- ‘My GP does my annual tests, but doesn’t explain the results to me – I’m just told ‘everything is alright’
- Better education of what diabetes is, is needed for GP’s and patients around the complications it can lead to
- There is a lack of explanation about the seriousness of diabetes when people are newly diagnosed
- ‘But I felt that I was given too much information when diagnosed, without any real explanation. And some of the information about diet was questionable’
- There should be more information available about diabetes in GP Practices – leaflets, booklets etc. for people to take away with them – they seem to have a lot more about other conditions
- There is a lack of understanding from some Health Care Professionals about diabetes issues – for example the DSN within my GP Practice didn’t know how an insulin pump works
- Systems between services don’t talk to each other – i.e. hospitals and GP Practices. Health professionals should be communicating better with each other. ‘I have my blood tests done at the hospital, but my GP Practice then tells me I have to have them done again – but I refuse’
- ‘I was unable to have an operation because my blood sugar hadn’t been at the right level for the preceding 3 months’
- ‘I was originally told by my GP that I couldn’t have more test strips, and only got them when I challenged it’
- You can only access a podiatrist if you have a complication. Its difficult to get an appointment with the service at Heart of Hounslow
- ‘I have an insulin pump which last four years. But the funding for the accessories are only for 12 months, and you have to reapply every year. But they only send me 6 months of supplies at a time, rather than the 12 months I’m funded for’
- There is an insufficient number of DSN’s for the area (although this is a National problem)
- ‘The checks I receive at my GP surgery are too infrequent’
- ‘My GP changed my medication but didn’t give me an explanation as to why, or of the side-effects of the new medication’

- ‘I find that when I go to my GP about non-diabetes issues, the fact I have diabetes is used as an excuse not to address the issues – there is a lack of understanding in the GP practice’
- Health professionals are too quick to give medication, rather than pushing lifestyle changes
- All GP practices should have somebody trained to Warwick standards – but in Hounslow we don’t. There is a lack of education among health professionals
- There is a lack of knowledge of Type 1 diabetes from GP’s (although at the hospital it is very good) – or for Type 2 diabetes for those on insulin
- GP’s aren’t aware of programmes that patients can be referred to for further support (e.g. structured education programmes)
- ‘I agree with the lack of understanding of diabetes amongst GP’s – my child could have been diagnosed earlier had the GP picked up the symptoms’
- No information available from GP’s on hypos/hypers
- ‘I get told by my GP that my HbA1c level is too high, which I already know – but given no help to reduce it’
- Free swimming for diabetics is available in Richmond, should be available here
- Why can’t GP’s give booklet of information for each patient? Including general diabetes advice, but personalised information as well (in the relevant language, and including test results)
- ‘My GP (Feltham Centre) won’t take my 5 litre sharps bin for pumps’

### **Structured Education Programme**

- A number of people attended the X-PERT programme but thought that it was poor:
  - The content wasn’t good – it didn’t take into account other conditions you might have as well as diabetes
  - It wasn’t laid out well to be understood
  - I found the information to be generally good, but I disagreed with the portion sizes which they mentioned
- 2 people had attended DAFNE (1 person at Queen Mary’s hospital, another at Charing Cross). Both felt that it was excellent
- ‘I attended X-PERT, but it was delivered by a tutor not a health specialist – I think it should be by a specialist so that you can ask questions’
- ‘The X-PERT course I attended was delivered by a dietitian (at Heart of Hounslow). I thought the course was satisfactory, and any concerns I had I aired with them on the day’
- More should be done to educate children/parents about the risk of diabetes and their lifestyle choices
- ‘I had heard of the DAFNE course, but I wasn’t aware it was relevant for children too’
- A number of people had not known that education courses were available, but would be interested in attending
- The DAFNE programme was very practical, we had to maintain a food diary so had work to do as well
- Information should be available on-line, to allow people to self-learn if they would prefer
- There should be a choice of when you are able to go to sessions – including evenings and weekends
- The content needs to be tailored to take account of cultural issues regarding food
- Courses could be made available in libraries, leisure centres, mosques/other places of worship to make it easier for people to attend
- GP Practices would also be useful as they are closer (although not all with have the facilities)
- The referrals for X-PERT in the room had come through the DUK Voluntary Group – nobody had been referred through their GP
- Information should be available on-line about how, where and when you can get onto a course

- 'I found it useful to attend as part of a group of people with diabetes, as you learn from other's experiences – I've stayed in touch with people in my group'
- A web forum could be developed to address any questions people have after attending the course
- The length of each of the different programmes was fine with attendees
- Some people had been invited to attend a refresher course (for X-PERT and DAFNE), a year after the original course
- Exercise, as well as diet, needs to be a key element of the course content

#### **Future Involvement**

- Generally, people wanted to be involved again in helping influence services
- Preferably through face-to-face sessions, but it would be helpful to be part of a web forum/or be involved via email too
- The group felt it would be useful to have a joint session with GP's/ other health professionals
- Specialist support groups would also be useful – e.g. for those that use insulin pumps