

## Formation of a User Reference Group

### A REPORT ON THE FINDINGS OF A FOCUS GROUP HELD IN EREWASH – 5 AUGUST 2013

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#### BACKGROUND

Royal Derby Hospital are working with Diabetes UK to give local people with diabetes a chance to influence the diabetes services that they receive. The proposed approach was to establish an ongoing user reference group in each of the five localities served by Royal Derby Hospital to feed into an overall user group for the whole area. This in turn would feed into the Clinical Management Team. On 5 August an initial session was held with a group of patients from Erewash to gain their views on the approach, methods of recruiting users to the group and to gauge initial interest in being involved.

#### METHOD

Facilitation of the focus group was led by Alex Devereux from Diabetes UK, supported by Lisa Stone from Royal Derby Hospital and Mae Giordano from NHS Erewash Clinical Commissioning Group.

Three key areas were discussed within the focus group:

- Attendees were asked their views of the diabetes care that they currently receive (positive things and things that could be improved)
- The aims of the proposed Diabetes User Reference Group
- The expectations on people who would want to be involved on the group

6 service users attended the focus group, recruited through promotions within local GP surgeries and conversations held with local patients by the Diabetes Specialist Nurse. 4 of the attendees had diabetes, with the remaining two participants being family members of people with diabetes. All of the attendees were of white-British ethnicity

#### KEY FINDINGS

The below summarises the key findings from the focus group:

##### Quality of Care

Generally people were very pleased with the diabetes care that they were receiving locally. This seemed to be the case across different services including GP practices, hospital services and pharmacies. One person commented that he received all of the necessary checks, although these seemed to be part of the Well Man checks.

Despite this there were a number of areas that participants felt could be improved. There seemed to be a lack of communication between different health services, which was particularly apparent between GP

Practices and Royal Derby Hospital. For example one person had to have blood tests at both locations within a relatively short period of time. There was also an instance where one of the participants received a letter from his GP Practice warning of missed appointments when they hadn't actually missed any. A common view held amongst the participants was that there should be more information available about diabetes to further educate people about the condition. It was felt that this would also assist in the early diagnosis of people with diabetes.

### **Aims of the Proposed User Group**

It was felt that the user group would be a useful way of sharing good things that are happening regarding diabetes care in different GP Practices which people wouldn't otherwise hear about. It was also felt that a diabetes user group would be a beneficial way of improving the education of people about diabetes and as a method of communicating with different people. When asked about the general aim of the group as a method of giving people a means to influence local services, participants seemed a little sceptical. The question was raised whether there was any resistance from the Clinical Commissioning Group, while also making the point that a group would only be able to make an impact if the GP Surgeries were on board. One attendee also expressed a concern about the expectation that members of the service user group would be expected to seek the views of the wider diabetes community and represent their views, as they didn't feel that they were in a position to do this.

When asked if the user group is something that the attendees would be interested in, the reaction was mixed. One person in particular said that they would not be willing to commit their time to something, without further details on exactly what the group would be discussing as the draft terms of reference were too vague on this at the moment. Generally people said that they would be more interested in attending a meeting at which they are given information about diabetes services with expert speakers attending – rather than giving their opinions about services. Even then, people commented that they would attend occasionally (depending on the discussion points and whether it was something they were interested in).

### **Practical Aspects of the User Group**

The group commented that Erewash covers two distinctly different areas (of Long Eaton and Ilkeston) and that this needs to be considered carefully to ensure both areas are catered for. It was suggested that the meeting venue should be in between the two areas if possible to encourage attendance from both. It was recognised by the focus group attendees that they were not representative of the whole Erewash area and that more would need to be done to make an ongoing user group accessible to others. Examples included that some people won't want to be out and about in the evenings, while those that work wouldn't be able to make meetings held during the day. It was suggested that sessions should be held at different times to give people a choice over what ones they would attend. It was also noted that dates for meetings should be set well in advance to give people enough notice to attend sessions they are interested in and change plans to allow it.

The group were also clear that not everybody who would want to be involved and give their views on diabetes services would necessarily wish to attend a meeting to do so. Therefore it was proposed that alternative methods be available to give people this opportunity. It was particularly suggested that young people may not be interested in attending a meeting but may be willing to get involved in a virtual meeting hosted online.

## **ACTIONS TO BE TAKEN**

Following the focus group, Diabetes UK and Royal Derby Hospital have re-drafted the proposed Terms of Reference to make the following key changes:

- Rather than a reference group with a fixed membership, the group will be a series of events based on different diabetes-related themes agreed in advance;
- Each session will be promoted to the whole of the diabetes population in Erewash to attend;
- As the sessions are held and Royal Derby's network of contacts of local people evolves the idea of an ongoing user reference group with a fixed membership for diabetes will be revisited in a year's time.

## **APPENDIX**

Full notes from the Erewash Focus Group on 5 August 2013

### **Positives about care locally**

- Generally I'm very happy with the service I receive, with all of the different services I've seen – GP/dieticians. I have somebody I can contact with any diabetes-related issue I might have
- I agree that I'm generally well served by my GP Practice and the hospital. The pharmacies are also very pro-active and help people to understand their medications
- The service at the hospital is very good
- I receive regular checks – which is usually through my Well Man checks

### **Negatives about care locally**

- A lack of testing strips on prescription – I have to buy my own
- Seems to be a lack of communication between my GP Practice and the hospital – I have had to have blood tests at both in a short space of time. I have also received letters from my GP Practice about 'missed appointments' which I haven't missed!
- More information about diabetes is needed to educate people about the condition – this would help with earlier diagnosis

### **Purpose and role of the proposed user group**

- Is there resistance coming from anywhere? Have clinicians bought into the idea of a user group? Are the GP surgeries on board, as there needs to be a route through to give messages to them?
- The group could be a good way of improving education of people about diabetes and for communicating with people
- It would be a good way of sharing what's happening in different GP Practices, particularly of good things that happen
- There should be alternatives for those that don't want to attend a meeting – maybe virtual meetings, held online
- I would want specifics about what kind of things the group would be doing or discussing before I would commit my time to it
- I would be more interesting in attending something at which I'm given information about diabetes and local services
- I would be more interested in attending occasionally for meetings that are on issues that I'm interested in. It would be good to have speakers come to these to talk to us
- Afternoons are better for some people, who won't want to be out in the evenings.

- But people need to be given a choice because some people, especially those that work, will only be able to make late meetings
- There are two different areas within Erewash (Long Eaton and Ilkeston) – the venue needs to be in between the two, or have different sessions for each
- Could advertise the sessions in the local newspaper, and the Council magazine
- Dates for the sessions should be set well in advance to give people enough notice
- Pharmacies could help to give people information about the events. You could also use the screens in GP Practices