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## **Diabetes Care & Services in South Lincolnshire**

### **A REPORT ON THE FINDINGS OF FOCUS GROUPS HELD WITH SOUTH LINCOLNSHIRE CCG AND DIABETES SERVICE USERS MARCH 2014**

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#### **BACKGROUND**

South Lincolnshire CCG is working with Diabetes UK in order to give local people with diabetes the opportunity to influence the services they receive locally. In March 2014, the CCG undertook 2 focus groups one in the Welland area of South Lincolnshire and one in the South Holland area. These events were held to explore peoples' general views on accessing services; what was working well and not so well and supporting self-management. The CCG also offered an alternative virtual version which was available for young people and people unable to attend the meetings, amongst advertising of this it available and also sent to all schools within the area.

The following report presents the findings from these activities.

#### **METHOD**

The focus groups were jointly hosted by Diabetes UK and South Lincolnshire CCG, with Diabetes UK's Improving Local Services Together Project Team leading the facilitation and the note-taking, the groups were also supported by the Delivery and Development Team from South Lincolnshire CCG.

Two events were held one in Spalding (South Holland) and one in Stamford (Welland), publicity was extensive using patient networks; local media and social media.

The first event was held in the Patio Room of the Springfields Conference Centre in Spalding, this meeting was from 6pm until 8pm. The second event was held in the Gallery Room of the Arts Centre in Stamford; this meeting was from 1pm-3pm.

The event had a structured programme and focused on the following key questions to aid with redesign work going forward.

- What are your positive and negative experiences of local diabetic services?
- In an ideal world what services would you like to have?
- What can be done to help you better manage your own diabetes?

Public Health also supported the CCG to disseminate the information about the event and a questionnaire to all secondary schools councils in our area, to engage as many young people – who were unlikely to attend a public event in person.

## **PARTICIPANTS**

Participation was high with the attendance as follows:

- Spalding Event 20<sup>th</sup> March 2014 – 33 attendees
- Stamford Event 28<sup>th</sup> March 2014 – 22 attendees
- Of these 24 attendees were male and 31 were female.

South Lincolnshire CCG was pleased with the number people who attended these events – and this had been a result of the good publicity that the CCG had undertaken, prior to the event.

A full breakdown of the participants overall view of the event structure and information on whether they felt listened to can be found in the appendices.

## **KEY THEMES**

The following part of the report shows what participants felt were the positive and negative about local diabetic services and the key themes to come out of this which reflected their 'ideal world' of service provision and what would support with self-management. A full copy of responses can be found in the appendices.

### **Positive and Negative Experiences of Care**

Participants had a number of positive comments to make, including the care received from their GPs; the Diabetic Nurses and Practices. Patients felt they had good support and could get feedback from their surgery when needed, two representatives with children also commented on the Specialist Children's Nurse in the county, and how important this service was to them. Additionally to this the Retinopathy service was deemed good and most attendees felt they had received their checks when due and that staff were helpful.

Negative comments around service provision featured the need for more professionals to have education in diabetes and the services available; more education courses and information for diabetics and their carers/families; more access to foot care; preventative education; local services in the community at the same time/place and professionals to share information. These themes were reiterated in the following sessions and therefore are explored in more detail below.

In its basic format the following provides an outline of the split of comments and the categories they fell under. In total 369 comments were recorded at the event. Within this we recorded what individuals felt were positive and negative about services and 162 responses were positive and 193 were negative.

Looking at the 5 areas that emerged the breakdown was as follows:

- Education – 99 comments
- Access and Treatment – 51 comments
- Information – 54 comments
- Dietary and Exercise – 58 comments
- Podiatry – 64

The remaining 43 comments were general and did not really fall under any specific area.

### **An 'ideal' support services world and helping to self-manage**

These 2 areas have been grouped together as the key themes are replicated in each section and show areas that diabetics in South Lincolnshire would like to see improvements; changes and better access too.

### Education

Education amongst professionals and individuals with diabetes was the most common theme across both events; this is split into two main areas.

- Professional education: participants felt that local professionals required more knowledge and understanding of diabetes (both type 1 and 2). Within this patients identified the need for more knowledge around local services; obtaining tools to support for self-management; support to use these. It was also felt this was wider than GP practices; staff in hospitals needed more education to understand diabetes and the impact of lack of medication; wrong foods etc. and how to give medication if the person is unable to self-medicate.
- Education for the Individual: attendees felt that the DAPHNE and DESMOND (education courses for diabetics at diagnosis) courses were very helpful and supported people at diagnosis – however not everybody had been offered the course. It was also felt that the courses were not accessible to everyone as they weren't flexible for those that worked, or had family commitments. There was general consensus that courses in the evenings/weekends would be an advantage. Additionally they would like to access these courses more than once, when their situation changes or if they have multiple long term conditions that could impact on their diabetes. Individuals felt this would support them to better manage their condition and would also enable them to highlight changes that they may need to speak to a clinician about.

### Access and Treatment

The second key area was around how people accessed services and how they received treatment. A great number of participants want to see more local services and more flexible services, including accessing appointments at the same time for different procedures/clinics in the same place. Clinics should also be accessible outside core hours at weekends and later into the evenings to support those with commitments during the day.

Patients also felt that in conjunction with this they should have a 'key worker' who coordinated their care and were the main point of contact, and that as a patient they should be treated as a whole person at the same time, rather than disease specific – as many conditions/medications impact on each other.

### Information

Gaining access to information was also paramount, as the internet can give misleading advice. Patients would like their 'key worker' to have more knowledge and understanding of the services and support groups in the local area, to support with self-management. This could involve a pack of information and advice for patients who are also carers in case they become ill.

### Dietary Advice and Exercise

To support with self-management and reducing the risks of additional complications participants felt the area needed more qualified Dieticians to support with food and nutrition and explain the benefits of good nutrition as well as the impacts if not followed. Coupled with this people would like more access to weight management classes; exercise referrals and reduced rate/free exercise classes enabling them to lead a healthier lifestyle.

### Podiatry

The final key area to emerge was the ability to access podiatry services. Patients felt that they were unable to access regular appointments and it was costly. It was felt that there should be more availability and also these should be either free or at a reduced rate.

## **RESPONSE TO FEEDBACK**

Having analysed the feedback into themes, the CCG are now in a position to look at how we can comment on these and involve patients further to continue the process to redesign diabetes services in South Lincolnshire.

One of the strongest themes to emerge from the events was that people wanted to access services in a local manner that best fitted their needs. The CCG has already undertaken some joint working to address this, and are in a position to give an update on the progress of these steps taken. This approach is in a pilot stage at present and does encompass a number of the themes above in addition to accessibility, this is explained in more detail below.

### **Integrated Care Teams:**

In April 2014 the CCG ran a stakeholder event for professionals working within the South Lincolnshire area, this was specifically to look at how South Lincolnshire could better provide services in a more localised manner, and better provide for the patient. This was in conjunction with a bigger project called Lincolnshire Health and Care (LHAC), which is currently in the pre-consultation stage.

Overall this project aims to bring integrated care and support services to patients and support them with a care navigator, throughout their health and social care journey. There is an Early Implementer site for this project in Stamford GP Practices, who will be supported by the LHAC team to develop neighbourhood models and will be looking to do full patient and public consultation within the autumn.

The second project is similar in nature to the above project; however this will focus slightly more on pre Diabetes services and supporting self-management as well as looking at integrated care and support services locally. This pilot area is to be in Long Sutton as this was another identified area for the LHAC project but as Stamford was chosen the CCG felt it important to apply some resource to the South Holland area.

### **What is an Integrated Care Team?**

Integrated care means different things to different people. At its heart, it can be defined as an approach that seeks to improve the quality of care for individual patients; users and carers by ensuring that services are well co-ordinated around their needs. To achieve integrated care, those involved with planning and providing services must impose the patient's perspective as the organising principle of service delivery.

The objectives of integrated care are to:

- Improve outcomes and experience for patients
- Create access to better, more integrated care outside of hospital
- Reduce unnecessary hospital admissions, readmissions and length of stay
- Reduce unnecessary A&E attendances
- Reduce admissions to care homes
- Enable sustained independent living and self-care
- Enable effective working of professionals across the provider boundaries.

### **Patients In Control Project**

The project known as Patients in Control is funded by NHS England and the Kent and Medway Commissioning Support Unit is leading as the champions to support local CCGs to undertake meaningful patient engagement. By working with a small group of patients the project will look in more depth at what local people would like in terms of supporting with self-management of services and accessing them locally. The project will then use this information to work with the CCG to look at how this can be worked

into the redesign of services and local commissioning plans. This work is scheduled to take place in July/August 2014 for the initial discussions; we have sent information to the project to support identifying people in the local area; however if you are from the Long Sutton area and would like to more, then please contact us at 01522 573939.

The anticipation is that this project will also support with the learning for the education theme, and will enable the CCG time to develop the most appropriate way to increase the amount of education and learning that is available to both patients and professionals.

With regards to the education theme, the CCG has acknowledged that this is an integral part to quality services and therefore with this in mind will look at ways to address the situation with the involvement of patients to ensure it best meets patient needs and also supports the CCG work going forward.

## **APPENDIX**

### **Report**

April 2014

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### **South Lincolnshire Clinical Commissioning Group Report of Event Evaluation Forms**

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#### **1. Purpose**

The purpose of this report is to demonstrate how SLCCG used patient involvement and how this was received by attendees of the event. The events were run in order to gather valuable patient experience from diabetics within the South Lincolnshire area, in order to ascertain an account of what is working well; where improvements are needed and to explain the process to local residents. This information will support with the overall redesign of services for diabetics within the area.

#### **2. Overview**

Two events were held one in Spalding (South Holland) and one in Stamford (Welland), publicity had been wide using patient networks; local media and social media. In total 51 people attended the events (more actual attendees may have been present but this report is based on the evaluation forms completed on the day).

The first event was held in the Patio Room of the Springfields Conference Centre in Spalding, this meeting was from 6pm until 8pm, this event had 29 evaluation forms received. The second event was held in the Gallery Room of the Arts Centre in Stamford; this meeting was from 1pm-3pm and received 22 evaluation forms.

The event was designed and facilitated by Diabetes UK with a structured programme and focused on the following key questions to aid with redesign work going forward.

- What are your positive and negative experiences of local diabetic services?
- In an ideal world what services would you like to have?
- What can be done to help you better manage your own diabetes?

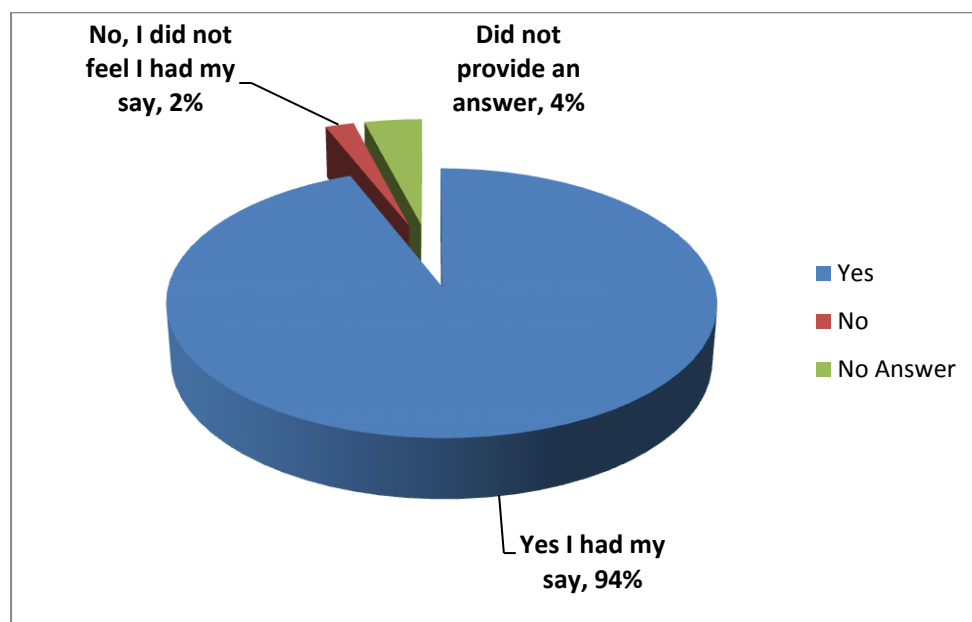
#### **3. Patients Voices & Experience**

SLCCG fundamentally sees the patient as being integral to services and their design, being regular users they have the knowledge and the experience. It is therefore paramount to us as an organisation that patients and the public have their voices heard and are able to share their thoughts and opinions.

Therefore one of the questions we ask is whether or not the patient thinks they have had their voice heard.

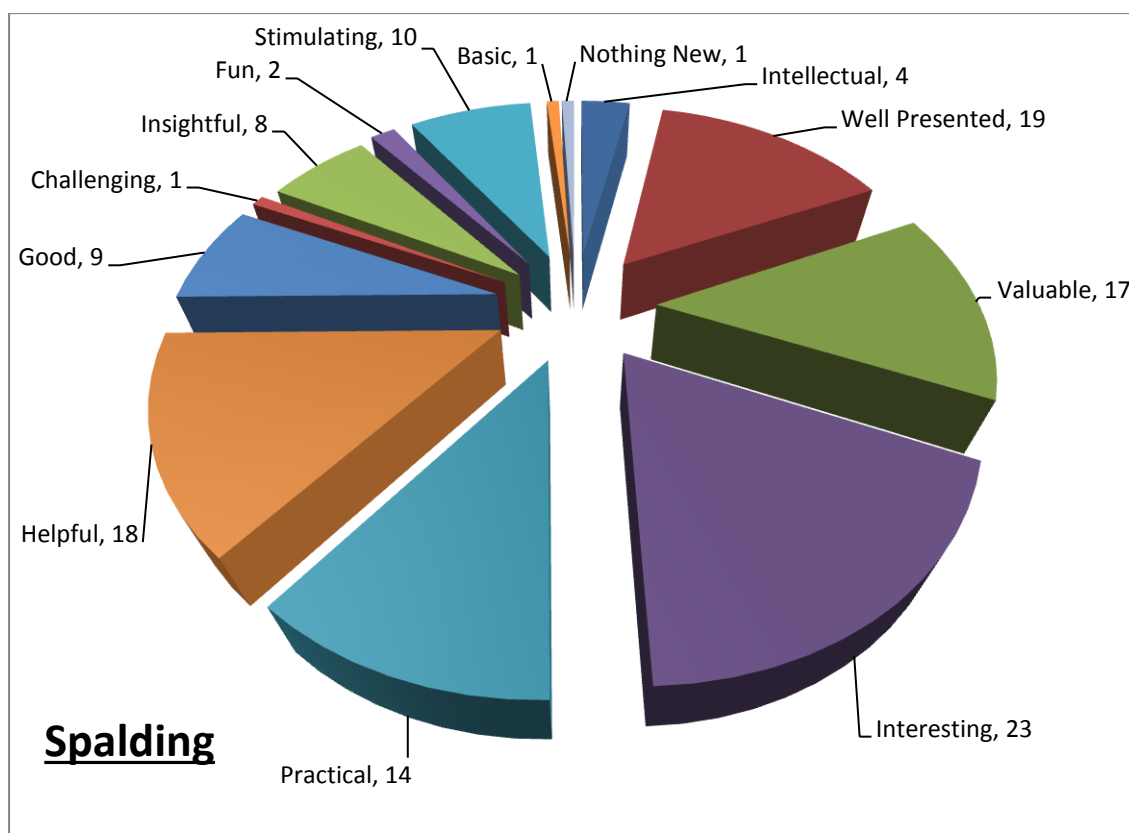
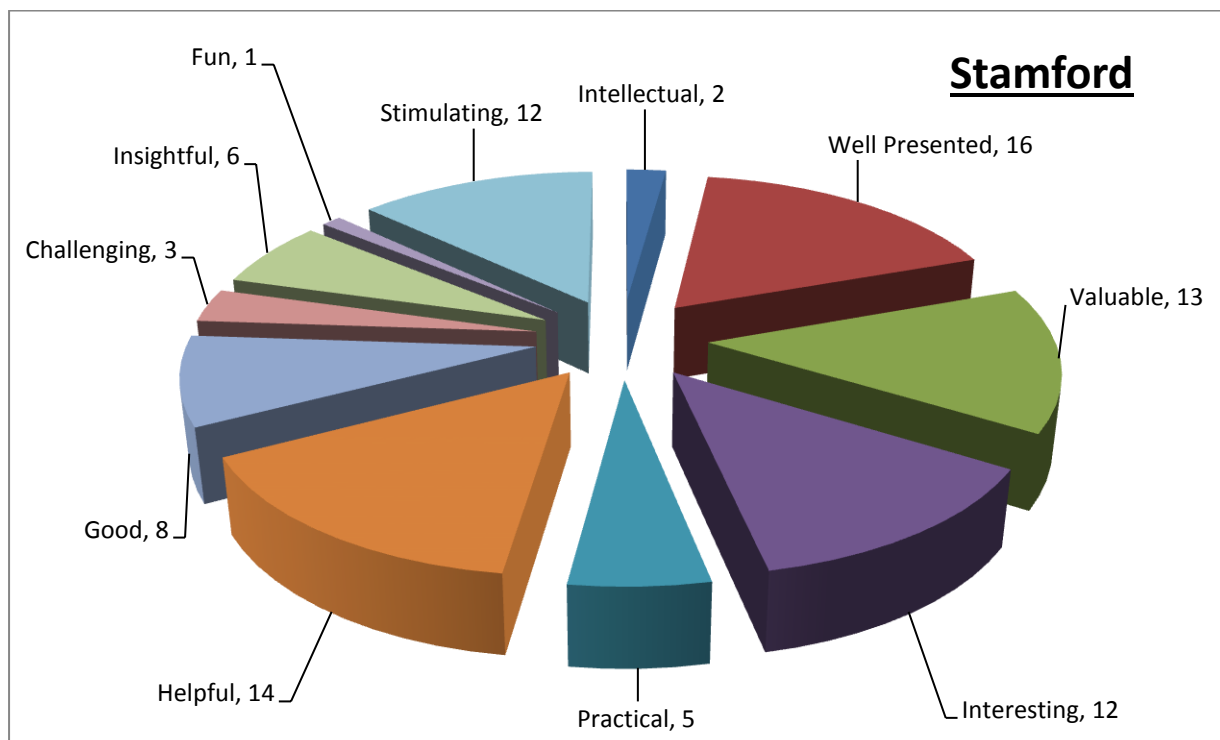
Patient response in this area was extremely positive across both events and showed that patients really do appreciate the time to have their say. 2 people gave no indication either way which represents 4% of the 51 evaluations. 1 person (2%) said they did not feel heard, but made a written comment that stated they felt able to contribute.

In total 94% (48/51 people) felt they had the opportunity to voice their views to be noted by the SLCCG – some of these were coupled with written comments of which can be found in appendices 1.



We asked the participants involved to pick up to 5 words which best described the event from a list of both positive and negative words. The results showed that this particular way of engaging with people is very positive, and people are engaged not only because they have a passion for the subject but also because they want to be involved in positive change.

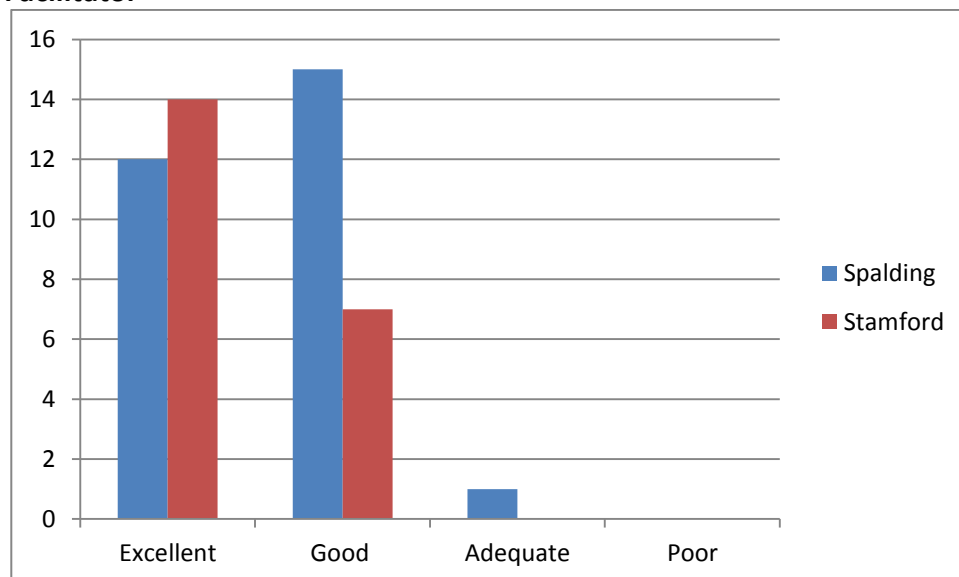
Both events had very similar experiences and found the event mostly well presented; helpful; valuable; interesting and stimulating. The full results are as below.



#### 4. Facilitator & Venue

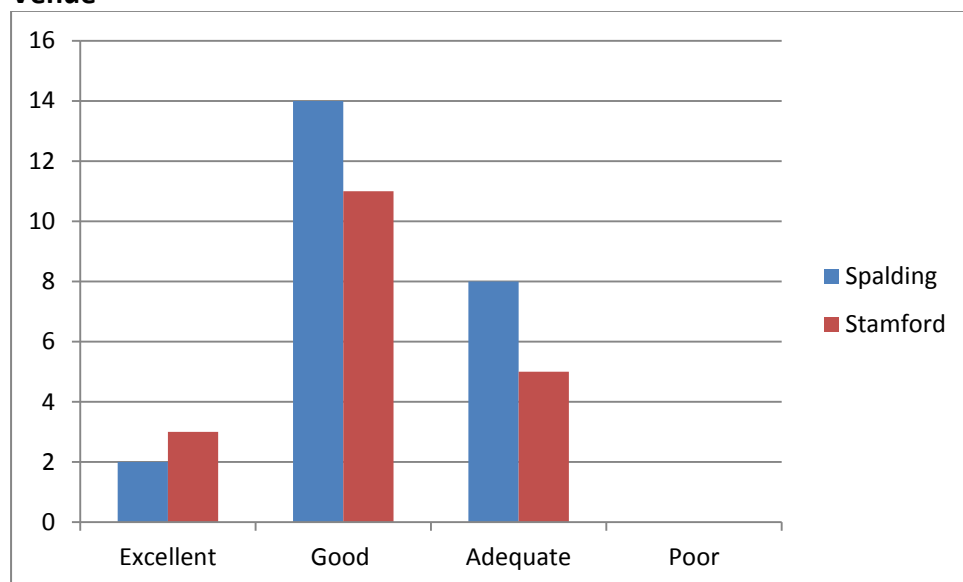
The evaluation also looked at the whether facilitators were useful on supporting tables and how well they undertook the task of gathering views and patient experience – the results show that this was positively received and useful – at both events.

##### Facilitator



For future reference of venue choice we also gathered information regarding the suitability of the venue. This had mixed reviews but both proved good venues for future events/

##### Venue



## 5. Conclusion

The evaluation of both diabetes events show that involving patients and users in events such as these not only supports the patient to have their voice heard, but the event itself gives the CCG the opportunity to learn from patients and will impact on services in the future.

The structure of this event showed that 94% of attendees felt able to voice their opinions and concerns and welcomed the opportunity. This coupled with the positive responses to words association for the event give grounds to run other project events in a similar structure.

The events also supported in members of the public learning about different ways they could be actively involved on a more regular basis, through Patient Participation Groups at surgeries and also through Healthwatch meetings, whilst encouraging a voice in one area these attendees were given the information they needed to be involved again.

## 6. Appendix One – Comments

General comments received about the events – for information.

- Well run event
- Looking forward to improvements – follow up meetings
- Having more GP's attend [the event] – as they represent the area
- [Was able to give] views on issues regarding diabetes and the little things the NHS not looking into
- Would of liked more time
- Guest speakers from other areas
- Felt pressured for time
- Got to have a voice
- Timing not good as 6pm is family time
- Not enough time to say everything
- Happy to help further with this sort of thing
- Meeting kept flowing and was productive
- Individual facilitators on each table a good idea
- 2 hours not enough – follow up sessions?
- Nice it [event] happened
- I hate icebreakers – we do talk as adults generally
- Nice to be included
- We will see if this has any effect
- Chance to talk
- Time constraints, more time to feedback – better with less introduction and icebreaker
- Eye opening
- [Favourite thing] meeting others with the same thing
- Raised issues not aware of
- Valuable
- [Favourite bit] interacting with fellow type 1 & 2 diabetics
- Had my say

- I was also listened too
- It was funny being sat next to me doctor. I hid nothing and now she knows everything hahaha!
- Nice to have opportunity [to have a say]
- Felt able to contribute [to have a say]

Full feedback can be found as the additional PDF attachment entitled 'Appendix feedback from Diabetes Event'.