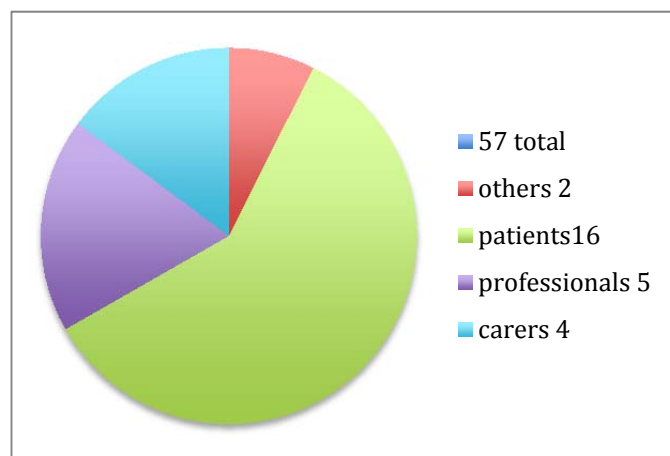


## FEEDBACK / WHAT WE LEARNT FOR THE FUTURE

As with any event, it is important to learn from our experience, see what went well, what didn't work and what knowledge we can bring to future events. Firstly, we learnt that we need to start preparing sooner. We had decided to provide all attendees with a pack of up-to-date information sheets. This was a good idea, but we needed to either start preparing them sooner or have more than one person doing them as they took a lot longer than anticipated to prepare.

## THE FEEDBACK FORMS

We had a total of 77 people register for the event, of whom 57 attended. This was not unusual given that many of us find we cannot attend events due to flare-ups of our condition. Those who attended were a mix of patients, carers, professionals and two others who were friends of people with the condition.



We asked a number of questions that were asked at the Birmingham conference as well, so that we could compare the events. Also, we needed to give feedback to the lottery who provided funding for the event.

WE ASKED HOW PEOPLE HAD FOUND OUT ABOUT THE CONFERENCE The feedback was interesting in that it covered such a wide range of mediums:

- Email notification
- Facebook
- Behçet's Forum
- BSS website
- Hospital poster
- Articles in newspapers
- Radio interview and the radio web page

This confirmed that we need to continue to advertise events across many mediums to reach the widest number of people.

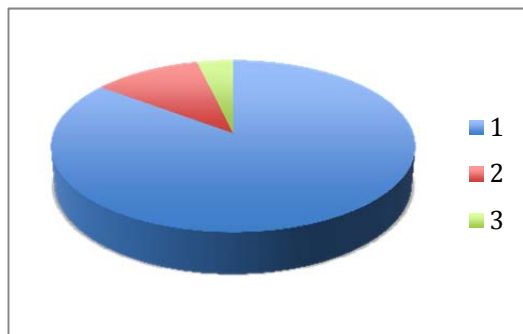
HOW EASY WAS IT TO FIND THE VENUE? While the majority of participants found it easy to find the hotel, 7% found it difficult to find. For future events, we would need to ensure that we provide better instructions on how to find the venue.

HOW DID THE LOCATION SUIT YOU? Among the carers, professionals and other attendees, there was complete agreement that the location suited them. However, 11% of the patients were unhappy with the venue. We would appreciate any feedback about why it didn't suit them and ideas perhaps for a more suitable venue.

ACCESS While 85% of people who completed the forms were happy with access, 14% had difficulties. There was one lift out of order on the day. We will feed this back to the hotel.

ACCESS TO FACILITIES There was variation in how people who completed the forms felt about access across all groups. 81% were very satisfied, grading it a 5, while 11% graded it 4 and 3% marked it 3.

REFRESHMENTS Overall, 85% of people were very happy with these, 11% graded them 4 and 4% graded them 3.



## CONFERENCE CONTENT

We asked three questions about this.

How relevant was the conference to you? 26 of the 27 respondents graded this 5, while one graded it 3.

How informative was the conference? 25 people graded this as a 5, and two people graded it at 4.

Overall did the conference meet your needs? 25 of the 27 respondents graded this as 5 and two graded it as 4.

We also asked people to indicate what was most useful

Meeting others with Behçet's disease.

Hearing from professionals: 11%

A mixture of both: 88%

WE ASKED FOR OTHER COMMENTS It was drawn to our attention that people with visual problems found it hard to see the presentations. This is a really important consideration, particularly as vision problems are a part of our condition. We will be seeking advice on this; if anyone has ideas, we would be really keen to hear them.

Another great idea is to put the conference on Skype so it can be accessed by those unable to attend the conference. Again, we have a lack of knowledge in this area and would really appreciate anyone with the necessary knowledge coming forward to advise us.

Other comments indicated that people welcomed a conference in Belfast, as before this people have gone to England for conferences.

We had ideas for other subjects including information on skin problems and vision problems, as well as more on research. We hope to run another conference in 2017 and will try to include these subjects. It would have been good to have professionals staying around longer to answer questions, but that would have been difficult as everyone gave us their time for free and wanted to fly home to spend part of the weekend with their families. If we hold a meeting during the week, many people would not be able to get away from their work/clinical commitments. However, we may be able to ask more local consultants next time who might be able to stay afterwards.

**Fionnuala McKinley**