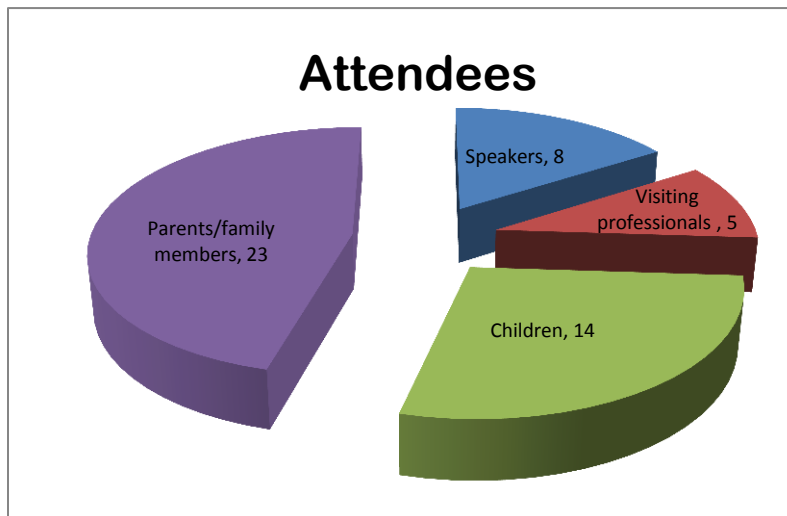
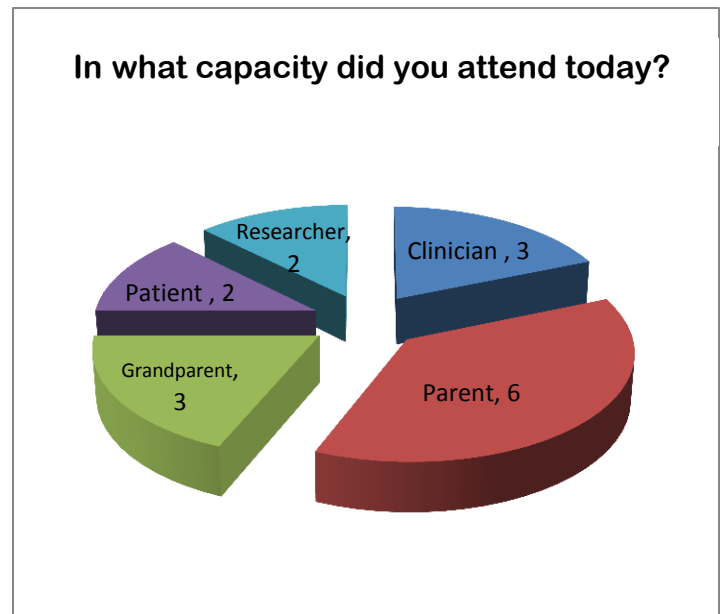


Feedback report from UK PH Patient Information Day Saturday 28th January 2017

Of the 87 individuals who registered, 50 actually attended the event. 4 families were unable to attend due to hospital admission or illness on the day, 2 were unable to obtain visas in time. The breakdown of attendees was as follows:



16 feedback forms were received at the end of the day, from which the following responses have been gathered.



Feedback report from UK PH Patient Information Day Saturday 28th January 2017

Attendees were asked how satisfied they were with various aspects of the day, where **5 = very satisfied**, **4 =satisfied**, **3 =neutral**, **2 =dissatisfied** and **1 =very dissatisfied**. There were no dissatisfied responses and only 2 neutral responses in relation to the time given for generation of discussions. 10 attendees reported that they were very satisfied with every aspects of the day. The talks satisfied everyone.

The results for each item are as follows:

Booking process and communications



Organisation of the day



Venue and facilities



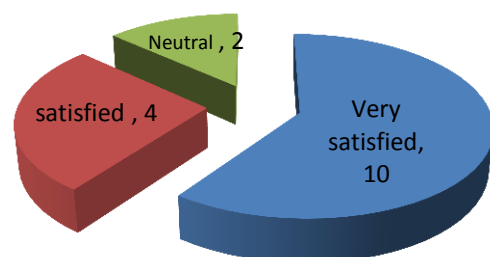
Catering



Talks that were delivered



Discussions generated by the talks



Feedback report from UK PH Patient Information Day Saturday 28th January 2017



The majority of respondents added comments to their feedback forms in terms of what they enjoyed about the day and whether there was anything they felt could be improved upon. All non-duplicated responses are presented below.

What did you enjoy about the day?

- Everything - Professor Danpure's presentation, Dr Patrick Haslett's information on progress of research and Fiona Gamston's information about transplants.
- Incredibly up to date information on PH, presented in an easily understood way by excellent, caring specialists. Many thanks to all involved.
- Staff was approachable and spoke plain English. Credit to all staff at Birmingham Children's hospital for arranging this.
- Meeting other families with the same condition and meeting the experts.
- Pitched at the right level and speakers were all very engaging, I was particularly impressed by the friendly support team.
- Everything – Dr Hulton is an amazing wonderful person to help us we are very lucky.
- The information and prospect of the future.
- Excellent information re – new research
- Informative and clarified what I already knew.
- Excellent talks

Feedback report from UK PH Patient Information Day Saturday 28th January 2017

What did you enjoy about the day? (continued)

- Families in the UK are very blessed to have someone as passionate and caring as you, your commitment to helping our community is such a beautiful act of kindness.
- Very informative – more so than local team in Edinburgh.
- Understanding studies into diagnosing and research.
- Professor Danpure's excellent explanations and finding out so much information we didn't know.
- Very well organized, pleasantly surprised re – catering.

Is there anything you think we could improve on?

- Frequency
- Nothing at all
- More discussion time
- No the day was perfect
- Greater time allocated for questions/interactions with speakers.
- Seemed a bit rushed