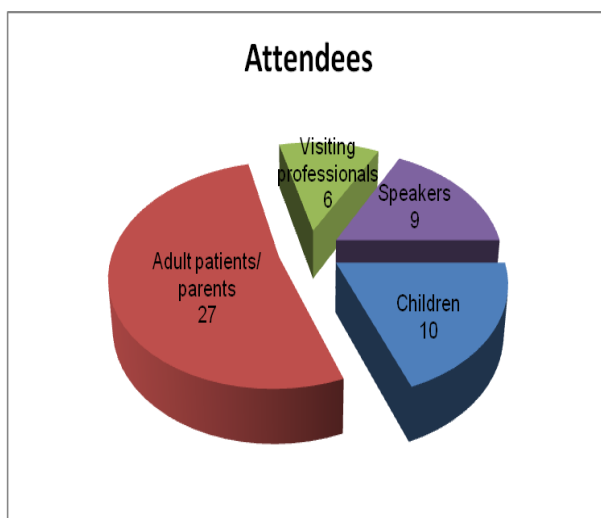
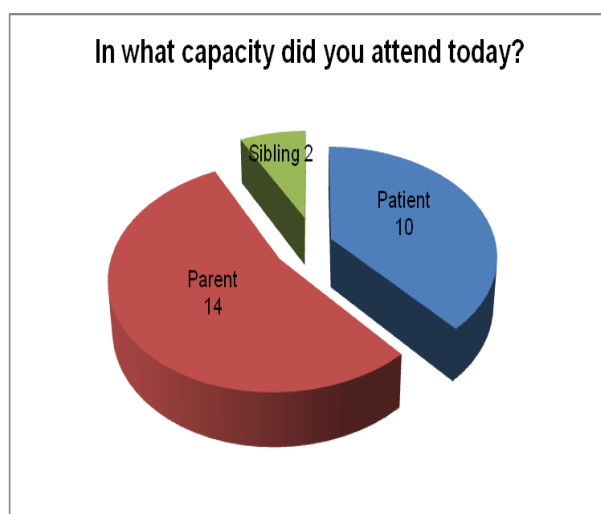
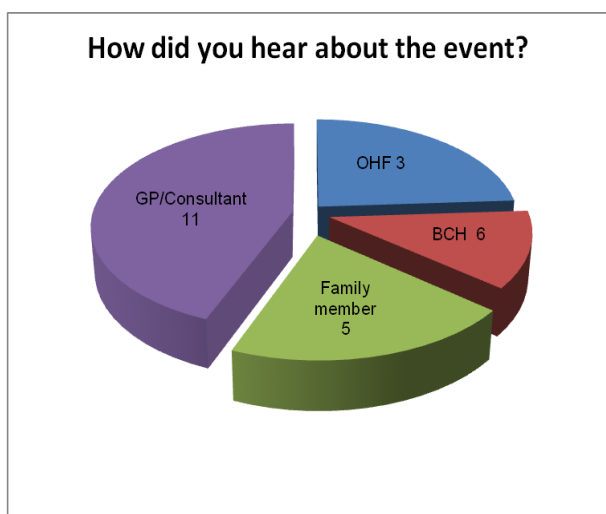


## Feedback Report from PH Patient Information Day Saturday 27<sup>th</sup> April 2013

Of the 80 individuals who registered, 52 actually attended the event. The breakdown of attendees was as follows:



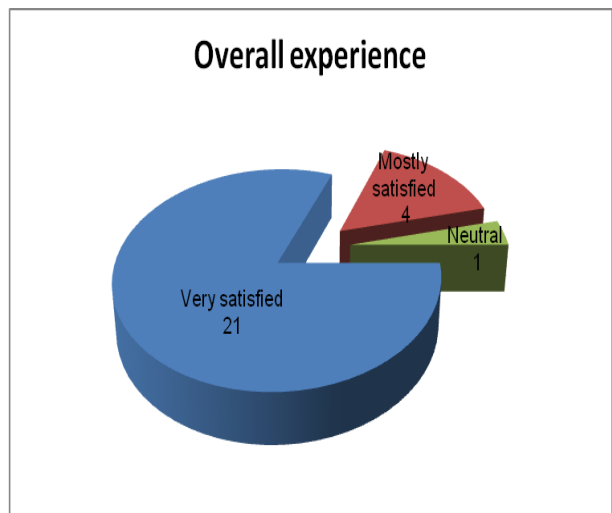
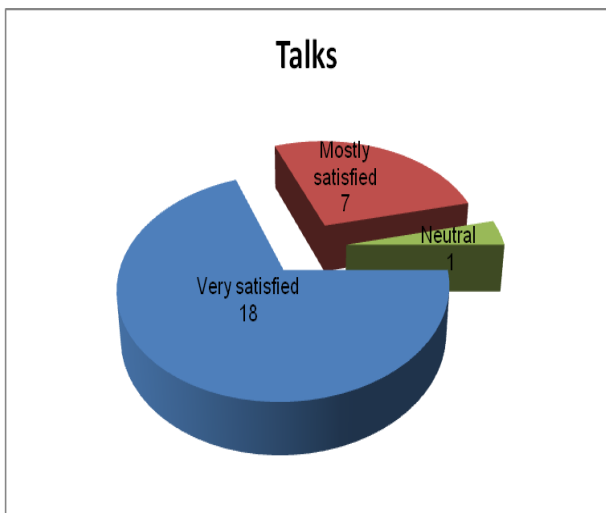
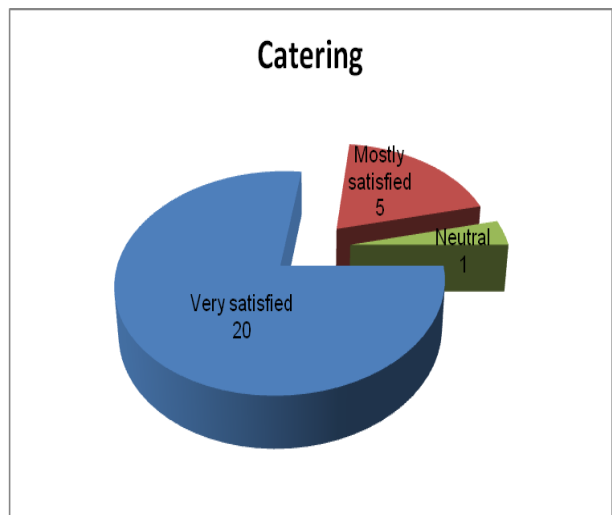
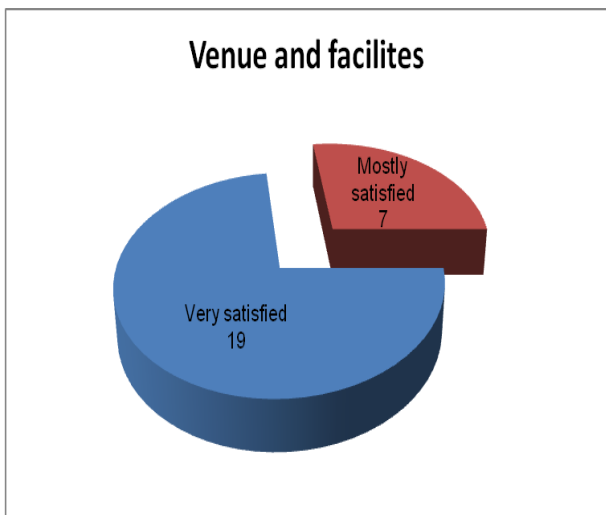
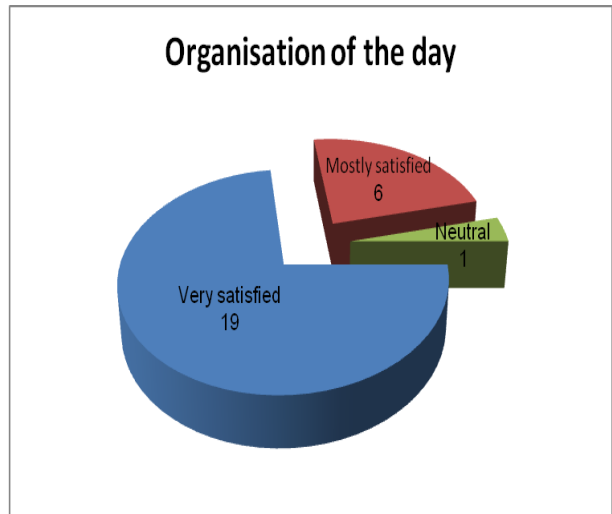
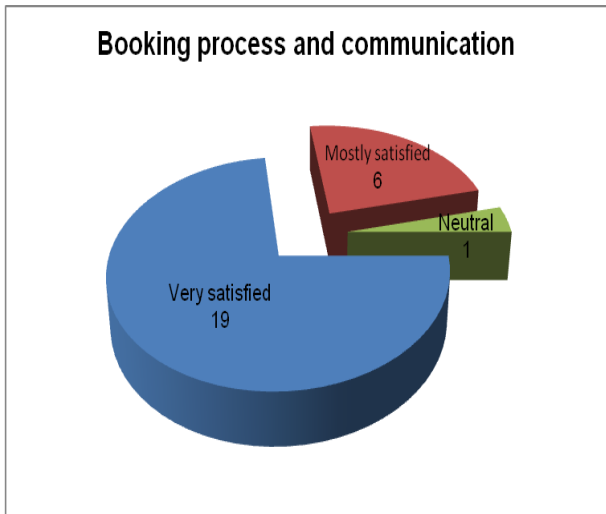
26 feedback forms were received at the end of the day, from which the following responses have been gathered.



Letters were sent out to all BCH patients inviting them to the Information Day. Nephrologists across the country were also contacted by e-mail and asked to inform their own patients of the event. Direct contact from the patients' GP/Consultant was the most effective means of communication in that it resulted in the most attendees.

The majority of attendees were parents of affected children. There was also a high percentage of adult patients and likely some cross-over between these two groups.

Attendees were asked how satisfied they were with various aspects of the day, where 5 equalled **Very Satisfied** and 1 **Very Dissatisfied**. There were no **Very Dissatisfied** responses and very few **Neutrals**. 10 attendees reported that they were **Very Satisfied** with every aspect of the day. The results for each item are as follows:



These are very encouraging findings and show that the day was viewed extremely positively by the vast majority of attendees. To have no 'dissatisfied' responses is brilliant!

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?**

- All of it!
- Meeting other patients and getting a biological explanation of PH
- Transplant surgeon and Urology talks
- I have learnt more in one day than in all other hospital appointments
- Fantastic – interesting day!
- Explanations of technical information given in an understandable way
- Chance to ask questions
- It was all enjoyable and important
- The whole programme was professionally done
- The up-to-date information
- I found it worthwhile that all questions were addressed and answered fully. All aspects of the condition were covered.
- Good to hear about new developments and treatments for PH
- In depth analysis and the videos of the treatments
- Learning more about the research and history of PH
- Very good facilities and food. Felt welcome
- Sharing experiences
- Learning information I hadn't heard before
- It is always nice and instructive to listen to Chris. We liked all presentations
- Transplant, kidney stone and biochemistry talks were very good

### **Is there anything you think we could improve on?**

- Not at all – very good
- Possibly a few handouts
- Could add a map to the place for those coming from outside Birmingham
- I would be grateful to have the opportunity to attend future events
- Too much information about transplants
- Private questions should've been answered privately – waste of time for others who it's not relevant for
- Some of the day felt a bit rushed – appreciate that there was a lot to get in but more breaks to enable informal questioning would have been good
- If we weren't connected to the OHF on Facebook I don't believe we would of heard of this via our consultant
- Confirmation e-mail after booking
- Long journey to Birmingham from abroad
- Timing – allow more time – 30 min time slots very tight. Some information was very technical and aimed more at clinicians than families
- Maybe leaving 5 min breaks between talks so nothing is missed by people needing a short break

Several of our guest speakers have also provided feedback and their comments are presented below.

**Kim Hollander**

I think the day went very well. I agree it would have been great to have more time for questions & a close out but it is always challenging to find the perfect mix. I do think many of the talks were really helpful as many patients really did not understand the basic science and genetic information. Also, I have to let you know that the urologist that spoke was absolutely fantastic and would be a great addition to the PH community.

**Sally Hulton**

The day was indeed a great success and the patient feedback has been excellent. My impression that more time was required for discussion is borne out in the comments and this can be addressed on future occasions.

**Christopher Danpure**

I thought that the patients' meeting went extremely well. I just wish I could have stayed longer to talk to the patients. Unfortunately, I had to cut across to the OxalEurope meeting. It was a joy to meet up with two patients who I had not seen since they were little girls. Thank you for inviting me.

**Gill Rumsby**

I'd like to congratulate you on a well run day. The people I spoke to certainly seemed to get a lot out of it.

**Daron Smith**

It was a good day - the young man with PH2 I was sitting with told me he'd learned more about his condition in the morning alone than he had in the whole of the rest of his life! I could only agree with him as I thought that Chris and Gill's talks put the condition into perspective very nicely - I learned a lot too! The discussion was indeed useful, but made the afternoon feel rather rushed in comparison with the morning. They were clearly a very interested audience, and the questions needed to be answered to their satisfaction.

**Bernd Hoppe**

Thank you very much for organizing the meeting!!! It was a pleasure being there and I am very happy that the parents and patients felt it interesting!