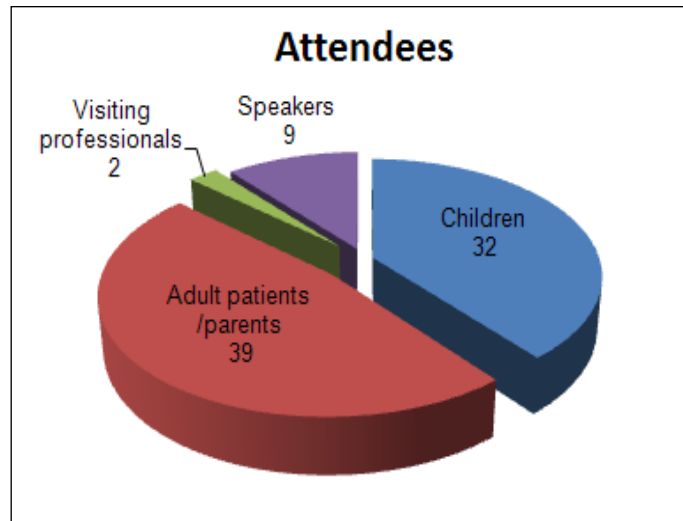


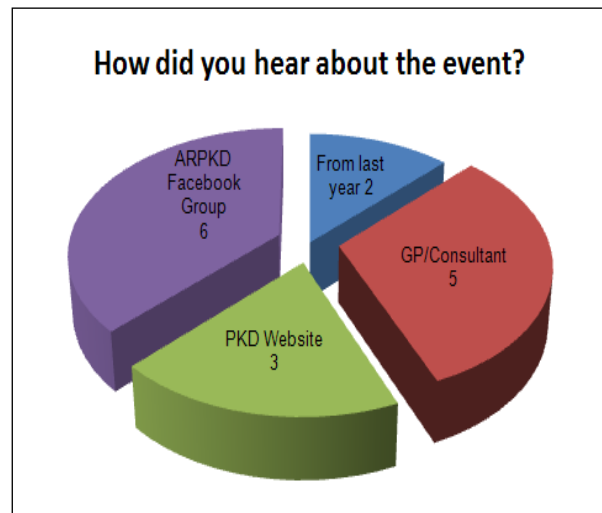
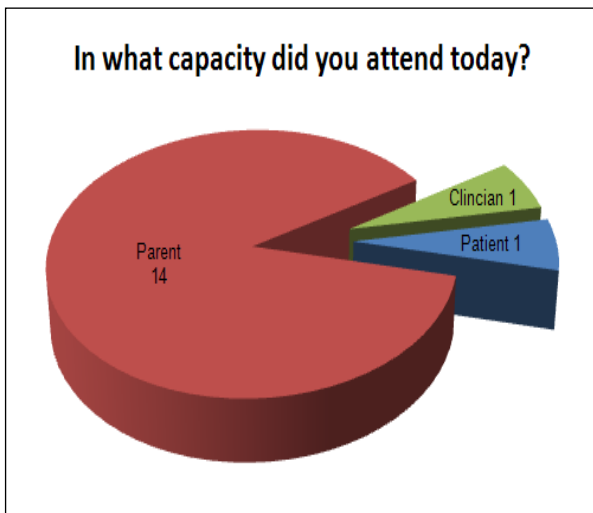
Feedback Report from the ARPKD Patient Information Day Saturday 6th July 2013

Of the 67 individuals who registered, 82 actually attended the event. This included one family from Norway, two from Scotland and another from Northern Ireland.

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.



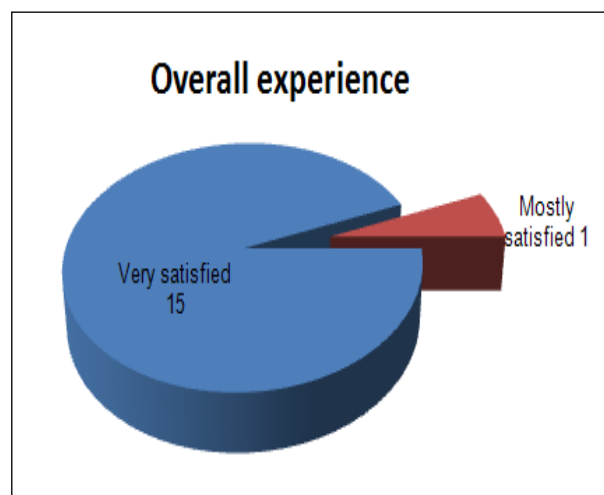
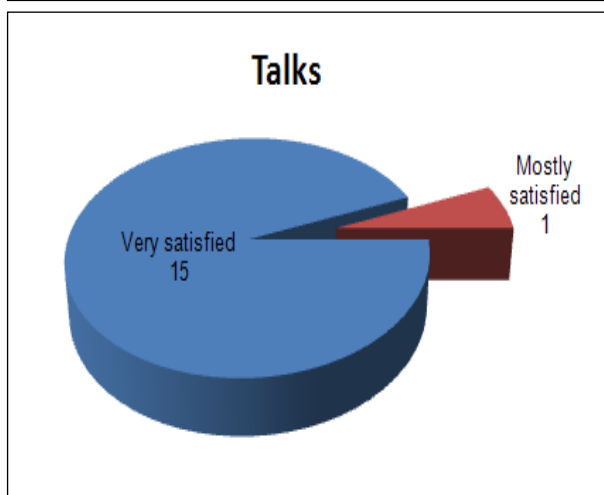
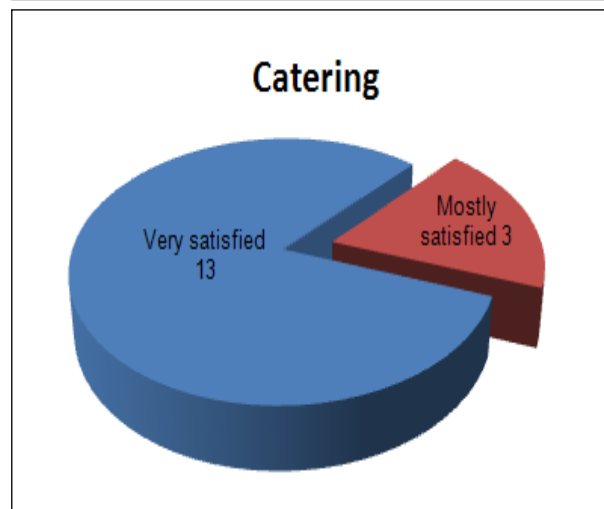
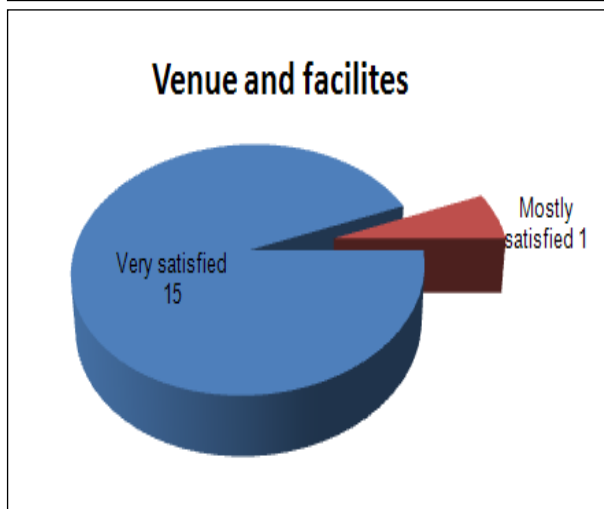
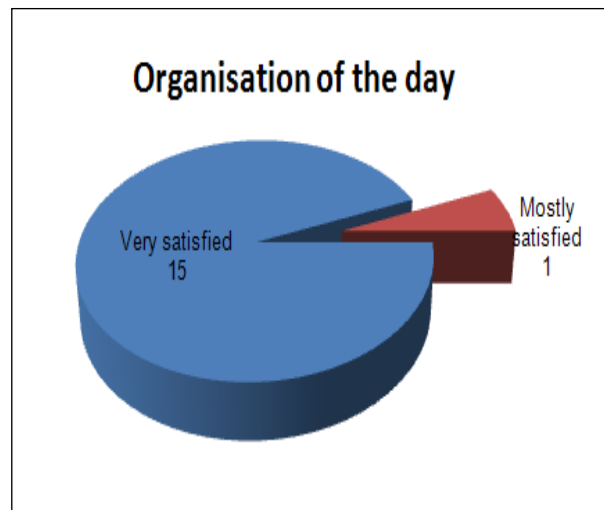
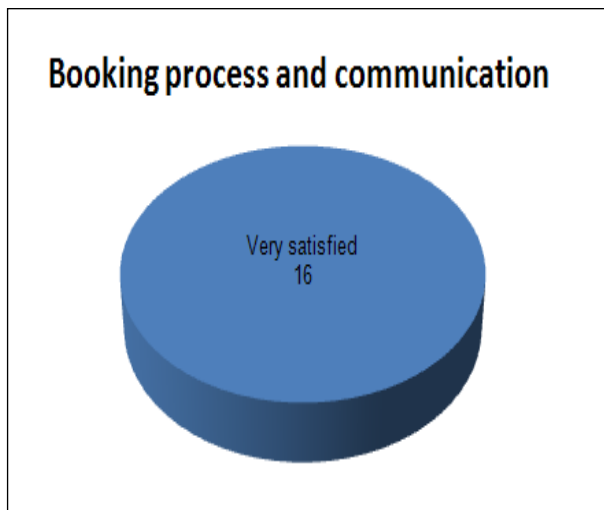
The vast majority of attendees were parents of affected children with adult patients in the minority.

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. The ARPKD Facebook group and direct contact from the patients' GP/Consultant proved the most effective means of communication in that they resulted in the most attendees.

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** or **Neutral** responses.

13 attendees reported that they were **Very Satisfied** with every aspect of the day. All 16 respondents reported that they were **Very Satisfied** with the booking process and pre-event communication, a testament to the excellent organisation of the PKD Charity who co-ordinated this 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?

- Meeting other patients/parents/speakers
- The liver-kidney transplant talks
- I thought it was so informative and I really enjoyed meeting other parents who were potentially on the same journey as us
- Sharing experiences and information
- The prenatal and transplant talks
- Getting good information from experts
- The variety of information from the doctors/speakers
- I enjoyed the genetics talk very much
- Gaining more knowledge from different people we'd not met before
- Making new friends
- Receiving lots of information on ARPKD
- Good to put names to faces especially for people who are going to be involved in our child's care
- The talks and presentations
- Liver aspects

Is there anything you think we could improve on?

- No - really enjoyed it
- Too warm in the lecture theatre
- Maybe have a translator
- More about any medical advances
- Found the genetics talk quite hard to understand
- More parents/patients to talk about their experiences
- It would be nice to spend more time talking in groups