Feedback of results

Q1. How did you receive feedback on your child's results?
- Received results by telephone 5 / 8
- Received results by letter 7 / 8

Q2. How would you prefer to receive these results in a different way?
- Face to Face 6 / 8
- Other - Please comment here No comments

Q3. When the Triac trial is completed worldwide would you like to know the results?
- 100% agreed

Q4. How would you like this information – Please tick all that apply
- A copy of the final scientific paper written on the trial 7 / 8
- A written letter to my child only 7 / 8
- Specific medical test results on my child only 6 / 8
- A 'lay summary' of the whole trial results 7 / 8
- Other (please comment) No comments

Follow up and Improvement

Q5. Are you or your family member more likely or less likely to be involved in any research trials in the future?
- More likely 6 / 8
- Less likely 1 / 8
- Don’t know 1 / 8

Q6. I was able to contact the research team when I needed to
- 8 / 8 Strongly agreed

Q7. Overall, was your experience of the trial at Addenbrooke's Hospital what you expected?
- 5 / 8 replied no, 3 / 8 replied yes

Parents comments

"The staff involved in the trial are absolutely amazing, second to none. They have treated us with the utmost respect and dignity. When the trial is over we are going to miss them very much.

"We felt like we were at home.

"We had no real idea what to expect so we were very pleased at the level of care and professionalism shown to all of us at all times."

"We would definitely like to take part in future research."

Conclusions

- Feedback from the questionnaire on staff, infrastructure and organisation of the trial was universally positive.
- Feedback suggests that play and entertainment facilities could be improved – our team will work with staff on the CRF to obtain toys and games more suited to children with severe disabilities.
- It is possible to conduct research on vulnerable populations if infrastructure and staff experience are appropriate and targeted to the participants needs.
- The results from the trial can be a substantial experience for children with rare diseases and their families, and can encourage patients to engage in further research. For this reason, researchers should not be deterred from recruiting such individuals to clinical trials, especially since they are a group of patients who may benefit from such research.

Reference:
1. Unicef – Children and Young People with Disabilities Fact Sheet 2013

G Lyons, A McGowan & C Moran
Wellcome Trust-MRC Institute of Metabolic Science, University of Cambridge, Cambridge