NIHR/Wellcome Trust Clinical Research Facility Cambridge Children's Non-Executive Research Board

By The Children's Board Strategy Group [1]

The National Institute for Health Research (NIHR)/Wellcome Trust Cambridge Clinical Research Facility (CRF) for Experimental Medicine is part of **Addenbrooke's Clinical Research Centre (ACRC)** [2] at Cambridge University Hospitals NHS Foundation Trust. In 2013, a Children's Non-Executive Research Board was established at the CRF.

The Children's Non-Executive Board has enabled children to have a voice in the service development of the facility. It includes children who have participated in studies on the CRF (originally recruited from a peanut allergy study and an artificial pancreas study), children who have never participated in research, parents and members of staff. The Children's Board meets twice a year and welcomes new members. Thirty-five children have signed up to join the Board and there are six main members who sit as active participants. The children are aged from 5 to 16 years old, with the most active members aged from 5 to 9 years old. At the first meeting they were asked to try out the equipment in the CRF. They were also asked for their opinions about research and all their comments were fed through to the agenda for the next meeting. This has created an ongoing process, enabling their voice to be heard.

The Board enables children to input into the design of generic and research study specific patient information. This includes input into patient information sheets, using language that other children can relate to so they understand the research.

The Children's Board has also had input into service re-design. They have provided input into the way we prepare children and young people before they come to the CRF in terms of the information we give, and also into the way we prepare rooms for children and young people on the day of their visit. They have made suggestions that have helped researchers provide an environment where children would like to spend time and participate in research. The ideas the children brought to the sessions have helped create brighter, more colourful child-friendly rooms, including the design and decoration of a new paediatric phlebotomy room (where blood samples are taken). The children have also had a say in what toys, DVDs, games, books and other resources (e.g. iPads and a children's activity menu) are available.

The Children's Board input has helped create age-specific photo story books about taking part in research for age groups under 6 years, 6-10 and 11 plus. At the first meeting there were ideas on how to redesign the website (**www.cambridge.crf.nihr.ac.uk**) making it better for children and young people. Through the Children's Board the CRF has been able to develop its understanding of the patient experience. It shares research-related stories more widely with visitors, staff, patients and members of the public, using case studies and a news bulletin board featuring 'good news stories'.

The Children's Board work has fed into the wider context of the CRF. This has influenced the NHS Allergy and Diabetes clinics which have gone on to use the photo story books to develop their own for local use. This work has also influenced the development of the Children's Patient and Public Involvement (PPI) group in Southampton.

We are carrying out a small study, Children's Experience of Engaging in Research (CHEER), designed to discover what

children, mums, dads, brothers, sisters and CRF staff think about the Children's Board. A focus group is being planned for April 2015 to explore experiences of older children and young people to inform our service.

The CRF believes that excellence in research is best achieved by involving and engaging patients in its work, to inform the way services are delivered and developed. This improves the patient experience directing effort into where it can add most value. The priority is to put people first, involving patients and the public in the work of the CRF. The ongoing work with the Children's Board is enabling the CRF to deliver excellence in research in a meaningful way, to those that matter the most, the patients.

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[2] Led by Professor Krish Chatterjee and Caroline Saunders (Head of Clinical Operations), the ACRC comprises a modern Clinical Research Facility and the NIHR Clinical investigation ward as well as the new CRF Satellite Unit. The facility offers round-the-clock care for research participants.

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