



The voice of children,
young people and families

Research & Us^{*}

Infants', Children's and Young People's
Child Health Research Charter

What you need to know

RCPCH

Royal College of
Paediatrics and Child Health

Leading the way in Children's Health

Infants, children, and young people have a right to high quality healthcare and health services. In 2012 in our report “Turning the Tide”, we showed how under-represented infants, children and young people are in clinical research that is essential to obtain evidence of what treatments, medications, services, and policies work, and are effective.

Parents and young people told us that they wanted to be involved in and benefit from research, and that their voices should be heard. This “Charter” has arisen from that appeal.

I commend it to everyone who strives to improve the evidence-base for healthcare through rigorous, high-quality research, whether you are a clinician, a manager, a policy-maker, or a developer of pharmaceuticals or devices. This is the voice of children, young people, and their parents and carers; they will help you to help them.

Listen to their voices.

Professor Neena Modi

*President, Royal College of
Paediatrics and Child Health
April 2016*



An Infants', Children's and Young Peoples' Child Health Research Charter

Why do we need a charter?

The purpose of this charter is to provide guiding principles for working with and involving children and young people in research. These principles assert the interests of children and young people, protecting and promoting these interests, by describing factors that are important to them. It also highlights the need to appropriately involve children and young people in all stages of research, from the development and design stage to dissemination of results.

Why is research with infants, children and young people important?

Research with infants, children and young people is essential to improve our understanding of childhood disease, and provide healthcare based on the best possible evidence. Currently child health research is not given the same presence as adult research. It is important to remember that children are different from adults. Their bodies respond differently to treatments, they have different opinions, and what matters to them may be different to what matters to the adults around them.

What is research?

Research is core to health and social care and is essential to improve infants', children's and young people's health and wellbeing and the care they receive. Research improves the evidence base, reduces uncertainties, and leads to improvements in care. There are many types of research that infants, children and young people are asked to take part in, some will involve healthy individuals or individuals with a disability, long term condition or illness.

This charter also extends beyond research to include service evaluation, audits of practice, public health surveillance and sharing experience of a certain condition.

What are the benefits of involving infants, children, young people and families in child health research?

There are multiple benefits of involvement for the individual, community and the wider health and social care sector.

Key benefits include:

- empowerment of children and young people
- delivery of person centred care
- development of evidence based treatments
- support for further funding and resource allocation to child health research
- ensuring the focus remains on infants, children and young people
- creating child and youth accessible research processes and materials
- greater understanding of the needs, experiences, perspectives and attitudes of children, young people and families
- establishment of networks for future involvement and long term engagement professionally and patient focused.

By working with children, young people and families across all stages of research design, implementation and dissemination, healthcare professionals have access to experience, ideas, views and insights to support their work.

How do I use the Charter?

The charter's guiding principles provide a framework for you to work with infants, children, young people and families to carry out research. There are links to external resources and guidance on child health research, communicating with children and young people, and other topics, available to download at www.rcpch.ac.uk/cyp-research-charter which will support implementing the charter's principles.



The making of this charter

Through a series of consultation workshops and survey responses in 2015/16, 74 children and young people and 57 parents, carers and child health professionals spoke to us about their understanding and feelings about child health research.

Children and young people were clear that they wanted to be given the opportunity to be involved in research design, as a research participant, and to have the chance to help other children and young people. They wanted to be able to hear from and share experiences of child health research with others.

The groups also wanted professionals to speak about research positively, to choose words carefully that didn't have potential negative meanings such as "trial" or "investigate" (both made children and young people think about errors and mistakes) and to always give them a chance to speak to professionals so that they can understand what is going on and be involved in making the decisions.

In February and March 2016 the charter was released for external consultation, with individuals and organisations invited to comment and provide feedback.

A range of individual professionals (research nurses, research teams, clinical academics), organisations (Nuffield Council on Bioethics, Generation R, International Children's Advocacy Network, UNICEF and the Medical Research Council), parents, young people, as well as, the research leads for the UK paediatric speciality groups and paediatric clinical study groups, RCPCH led research strategy consultation committee and the UK Child Health Research Collaboration commented on the charter.

Parents, carers and child health professionals spoke about the need for increasing the commitment to child health research, with more time and resources needed to support researchers. Improving training and access to support materials was also important, as was having more health sector wide work done to ensure child health research is valued, supported and encouraged.

Definition of terms

The term “infants, children and young people” relates to from birth to the 18th birthday. In working with infants, children and young people it is important to take into account their individual needs, whether this be due to age, disability, communication preference, hard to engage background (e.g. young carer, asylum seeker, rurally isolated) or any other areas where extra support may be needed.

Child and youth participation/involvement in this document relates to Article 12 of the UN Convention on the Rights of the Child (1989) which states:

Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. 2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law”.

http://www.unicef.org.uk/Documents/Publication-pdfs/UNCRC_PRESS200910web.pdf



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Remember it's about me; involve and support me at every stage and keep me safe from harm.

Empower me, my family, and the people caring for me; help us to understand and feel more confident about research.

Support me, my family, and the people caring for me; give us time to understand research processes, how to assess risks and benefits, and what it will mean to be involved.

Engage with me and my family; listen to our questions and ideas, so we can help you to help us benefit from research.

Actively gain my consent or assent and explain my right to change my mind and withdraw at any time.

Rights are important to me; my right to understand research, be involved in decisions, be respected, and to help others benefit from research.

Communicate with me directly and clearly; make it easy for me to talk to someone about the research when I have questions or ideas.

Help others by sharing our stories; the things that worked and the things that didn't.



Go to www.rcpch.ac.uk/cyp-research-charter for more information about external resources and useful links to support child health research including:

- Opportunities to get involved in research
- Engaging children, young people and their families in research
- Involving children and young people in decision making in research
- Supporting and communicating with children and young people
- Websites and useful links

For more information or advice about research please contact the RCPCH Research and Evaluation Team at research@rcpch.ac.uk or to find out more about involving children and young people contact and_us@rcpch.ac.uk



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