

Researchers' responsibilities



"I think it is really important that the study is as personal as it can be - a personal connection between the researcher and the participants"

"I think that they really shouldn't think of all the participants as a whole group of people but more as individuals because everyone has different lives and it could affect them in different ways."

"Where the clinicians offering a trial took a leisurely approach, parents could feel that they too could take time to reflect."

"It is the little touches for example good manners, nothing is too much trouble, refreshments on arrival, individual care, someone to have done their homework about your child even if it just checking when their birthday is as I say it is the little touches. Researchers also need a good bedside manner :)"

"Research should be designed around the participant, and in consultation with them."



"So often I hear, from young people in particular, that they often participate in research but they never hear back about what happened."

"Among older children, researchers have a great responsibility for ensuring that both children and parents are equally informed about all aspects and potential discomfort of the research, including the knowledge that the research may not actually benefit themselves necessarily."

"Research in children is somehow still seen as remarkable, that only a small number of doctors and professionals will engage with, and that limited numbers of children will want to take place. A child's participation in research is too often seen as "exceptional", and to have overcome significant difficulties with ethics/RGD etc to have achieved that registration. This is erroneous."

"It may also be valuable to consider tailoring approaches to different research participants."

"Personally, I like seeing what my efforts have gone and produced, and how the information I give or the time I sort of give to do whatever it is... it's nice to see that they're bearing fruit, and actually having an outcome."

"Clinicians may have had little exposure or involvement in research. If better informed they may be willing to partake or encourage families to become involved in research."

As part of our project on the ethics of involving children in clinical research we spoke to over 500 children, young people, parents, professionals and others in the UK and internationally. This is what they told us about researchers' responsibilities. More at www.nuffieldbioethics.org/children

