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.”

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

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

“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/RSF etc to have achieved that registration. This is erroneous.”

“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.”

“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.”

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

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

“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.”

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.nuffeldbioethics.org/children
Making shared decisions about research

"I think ideally it's important to involve the whole family. A child is part of a family not really just themselves."

"... those from eleven onward, aah, those should make their own decision... Ours as parents is to try to help them..."

"I would always ensure my child was involved in decision-making processes, recognising her level of maturity and development."

"Children in particular need time, they need to know that we value their opinion..."

"If a child's, like, four or something - so is quite young - and then the parents want them to do research that maybe they don't want to do, obviously don't take their first answer, but I don't think you should force them into it."

"Well, you should let your parents maybe give an opinion but it is your choice!"

"... it's my decision [whether to take part], but if my parents thought it was a good thing I would want to know why."

"You should talk about it at home as they [parents] might have a good reason why you shouldn't take part in the research."

"The parent has seen the sun earlier so she has... I mean she knows a lot... she has experienced a lot and she has seen a lot... whatever she tells you, you can also think well about it, that parents love you unconditionally, she can never have bad intentions for you."

"The decision of whether a child participates in clinical research should ideally be a joint one supported by all parties, including the child."

"A key question of integrity is important, particularly in those cultures where children's rights are not emphasised and there may be undue and inappropriate pressure on a child from parent or community leader to become a participant in a study."

"I believe that my child has a right to be part of any decisions regarding his treatment and the risks they may be exposing themselves to."

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Inviting children and young people to take part in research

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Deciding what research happens

“A coordinated approach to funding can help to ensure key problems are addressed, encourage collaborative working, and to avoid duplication.”

“...charities set targets that they wish to achieve through their research funding activity, identifying gaps in knowledge and capacity and finding the most appropriate way to address them.”

“The list of research priorities should not be restrictive nor impede research in other topics that are novel and promising, but not well known yet.”

“...a consensus process should be developed among the key stakeholders to identify priority areas.”

“Those involved in decision-making should include Pharma and academia experts, also regulators and patients’ organisations.”

“...work is required to facilitate more effective partnership working in order to maximize impact and make best use of limited resources.”

“...research should be prioritised to the need of the country or population where the resources are to be invested... A second layer of decision-making is to determine, based on available evidence, where the research would make the most impact.”

“All stakeholders including researchers, funders, policy-makers and communities who are end-users of the interventions should be involved in making these decisions.”

“A professional panel, with the participation of all groups involved, should discuss, prioritise and encourage paediatric research as befitting the needs of the country.”

“If decisions do need to be made around priorities they should be taken by parent groups, professional organisations and charities representing these young people, and cannot be left to the pharmaceutical industry where they may see the profit margins as being very slim.”

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