

Statement of aspiration: improving research by involving children and young people

This statement was agreed following a meeting hosted by the Nuffield Council on Bioethics on 22 April 2016 to explore collaboration between life-sciences industry and young people to improve research. A full note of the meeting is available at: www.nuffieldbioethics.org/children-research/industry

- Collaboration between researchers and the people whom research aims to benefit has become recognised as the gold standard in ensuring that research is truly focused on the needs of future users.
- Such collaboration is valuable throughout the full research process, from the initial prioritisation of research topics, through study development and design (including the development of meaningful outcome measures), to the development of information and consent materials suitable for their intended audiences, and the dissemination of research outputs/findings.
- Collaboration may take many forms, but is clearly distinguished from market research and other ‘one-off’ approaches through its *partnership* nature: it should involve a genuine sense of dialogue and an ongoing feedback loop between researchers and patients/public. Partnership of this kind, undertaken with the genuine wish to improve the quality of specific research studies, should not be regarded as the ‘promotion’ of medicines to patients or the public. Clarity with respect to the nature of the partnership, the respective roles of those concerned, the time constraints, and the recognition mechanisms is important.
- Good collaboration is valuable and important whatever the source of research funding (public, private or charitable) and applies across all age groups.
- Children and young people have historically been seen as a ‘vulnerable’ group, so that research and therefore the evidence base underpinning their healthcare has lagged behind that of adults. Active collaboration between researchers and children, young people and parents provides an important means of minimising any risk that children taking part in research might be placed in vulnerable situations. Such collaboration enables researchers to be alert and responsive to the particular perspectives and needs of children and families throughout the research process, and can improve the understanding of the research offer by prospective participants.
- The UK has led the way in developing Young Persons’ Advisory Groups (YPAGs) within the National Institute for Health Research and the Scottish Children’s Research Network. These groups offer researchers, regardless of the source of their funding, the opportunity to obtain input from children and young people on their proposed study designs and information materials. An important feature of the YPAG model is the role of a skilled facilitator, who will ensure YPAG members are adequately supported and can act as an ‘honest broker’ between researchers/ research sponsors and the children and young people involved in the group.
- A secure funding mechanism for these groups, and for other sources of collaboration with children, young people and parents, needs to be found. Such a mechanism needs to enable potential collaborators to contribute openly and transparently to the costs of collaboration.
- Collaboration between young people and commercial researchers should become an established and normal way of working. Learning from this collaboration should be actively translated wherever possible to the adult healthcare/life sciences research setting.
- Further work is required collating and sharing the evidence on the impact of such collaboration on the quality of research and efficiency of recruitment and study completion.

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Signatories to the statement



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