

This response was submitted to the evidence call issued by the Nuffield Council on Bioethics' Working Party on *Children and clinical research: ethical issues*. Responses were gathered from 7 August to 31 October 2013. The views expressed are solely those of the respondent(s) and not those of the Council.

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Q14 What happens when the research is over?

I took part in research with my daughter when she was aged about 16 years. The researchers promised us sight of the final paper, but in each case we heard nothing further from them – no thank you; no acknowledgement, and certainly no papers. We spent a significant amount of time being interviewed. There was no monetary incentive – we just did it for the benefit of others. It was at a time when she was stable but still very ill and going through the transition to adult services.

THANKS:

- There should be a proper thank you to the child and an aspirational statement about the value of research. Some token of the time spent or something for the CV?
- Happy not sad notice. (The Avon study note is sad). Hope for the future for the sufferer.
- Any further information about the use of the research material, where it is published, etc?
- No artificial promises; an apology if not fulfilling an agreement.
- Kindness as befits clinical research – the children are people with minds too.
- Some information when the research project is finished and further thank you?