

Assessing the “ethics” of a research proposal involving children -

a framework we could share to develop fair research for children and their families

Fair research for children

Write your concerns and questions in the chat box AT ANY TIME. START NOW!!!

One of us will read them and put them in when relevant. We will have a Question and Answer session toward the end to review these.

If we don't know the answer, we will find someone who does!



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Our aim

To help delegates promote and facilitate research involving children in their area and community.

Our method

To open a discussion on what “Good Research Involving Children” might look like and to consider how we can promote this.

To engage with you, our audience.....

What is fair research (for children)

Questions anyone involved in research should ask.

**Well, its no
different from
any other
research!**

1. Is there justification for the study?
2. Is the study based on a clear understanding of benefits and an interest? (i.e. is the study necessary?)
3. Will the study be conducted in a way that offers a fair benefit to participants?
4. Will the study be conducted in a way that respects the autonomy of participants (i.e. informed consent)?
5. Will the study be conducted in a way that respects the confidentiality of participants?
6. Is the research team qualified to conduct the study and to provide appropriate care?
7. Does the research team have the necessary resources and appropriate views?
8. Is selection fair? (inclusion / exclusion)
9. Are participants recruited fairly?
10. Will the study be conducted in a way that respects the dignity and appropriate care?
11. Will the study be conducted in a way that respects the privacy of participants?
12. Will the study be conducted in a way that respects the confidentiality of participants?
13. Will the study be conducted in a way that respects the autonomy of participants?
14. Will the project be registered and results placed in the public domain?

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What does this mean for research involving children? Are there particular issues and if so, what are they?

Bob Phillips

ETO Defence

ECONOMIC

Just too costly to open up for the 1:10,000

TECHNICAL

Kids don't have same disease pathology/pharmacology

ORGANISATIONAL

The study site doesn't see children

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Panel

Questions and Answers from the chat line

- Hugh Davies
- Jenny Preston
- Bob Phillips

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Conclusions

What can our delegates do to promote research involving children in their community? What resources might help them

- Use the “14 questions”

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Helping members make good decisions



Phew!
The end!

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THANK YOU!



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References

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- iii. Kodish E. Ethics and research with children Oxford University Press
- iv. Preston, J., Stones, S.R., Davies, H. & Philips, B. (2019). How to involve children and young people in what is, after all, their research. Archives of Disease in Childhood 104(5): 494-500. Doi: 10.1136/archdischild-2018-315118.
- v. Phillips, B., Davies, H.T., Preston, J. & Stones, S.R. (2019). Framework to help design and review research involving children. Archives of Disease in Childhood 104(6): 601-604. Doi: 10.1136/archdischild-2018-315119
- vi. Davies, H.T, Phillips, B., Preston, J. & Stones, S.R. (2019). How to navigate the ethical review of research. Archives of Disease in Childhood 104(7): 697-700. Doi: 10.1136/archdischild-2018-315120.