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I am a paediatric ethicist and consultant in paediatric palliative medicine. I chair our local Clinical Ethics Committee and am on the ethics committees both of the BMA and the RCPCH.

It will be important that this document is credible to moral philosophers and ethicists as well as to clinicians. Outside clinical paediatrics, there is a good deal of scepticism about whether research in children can ever be justified if it offers no clear benefit to the individual child.

As I see it, there are two arguments that need to be made in order to persuade that it is ethically acceptable to do research in children. The first is easy – that research in children is necessary in order for children to be treated rationally (and therefore ethically). That case is rationally and empirically clear, and this paper makes the argument well.

The second argument is equally important but much more difficult, answering the question “When, if ever, is it acceptable for an individual child to participate in research?”. Most readers from a moral philosophy or ethics background will assume that doctors caring for a particular child have a moral duty that is compromised by recruiting her into research projects. This document needs to persuade readers that there are circumstances under which it is ethically permissible for an individual child to be recruited into a study that will do that specific individual child no good.

There are potentially four arguments you can use, all of which, it seems to me, need to be explicitly made in this document, but in fact only the last one is likely to be persuasive.

Argument 1: Participation might bring medical benefit to the participant. A specific research project might benefit that child (for example, a new cancer drug might cause regression of the tumour). The problem here is the obvious ‘equipoise’ one that if benefit is expected, the outcome is known so that the research is unnecessary and is not ethically justified for that reason. By definition, the benefit of well-designed research is not known beforehand.

Argument 2: The individual child doesn't matter if the gains to society are big enough. The importance to society is so great that the child's own safety and preferences are - relatively or absolutely - unimportant. This is an expression of the utilitarian consequentialist argument. Not many clinicians would support it, although some well-known medical ethicists from a philosophy background certainly would. It is largely inconsistent with RCPCH emphasis on the moral value of each individual child.

Argument 3: Parents are entitled to offer up their child to participate. The problem with this argument is that it characterises the child's own preferences as irrelevant – effectively, the child is seen solely as the possession of her parents. Again, this is inconsistent with the RCPCH emphasis on the importance of a child's own autonomy and the idea that the interests of child and parent may not be the same.

Argument 4: A child can recognise a moral duty to participate for the sake of others. It is entirely consistent with the view of most paediatric ethicists (and the RCPCH) that a child is already part of society, not simply a trainee adult. It is also consistent that a child is capable of altruism. There is a persuasive argument here that children who can engage with the decision process should be offered the opportunity to participate in altruistic projects such as research.

Whether children who can't engage with the decision process – including neonates – should be denied that opportunity for altruism is of course much harder to argue. I have sympathy with the argument that parents can give proxy consent in that situation, providing they are doing it because they think participation is what the child would want, rather than because they themselves get something out of it. Those two clearly can't always be distinguished in principle, let alone in practice. Given that, and the importance of nevertheless being able to treat those children on the basis of evidence as far as possible, I think it's reasonable to assume (cautiously) that even infants and neonates and children who are cognitively unable to articulate it do in fact see themselves as part of the world, and therefore plausible to assume some degree of altruism in them.

Finally, I think we need to limit the scope of research to questions that can only be answered in the population in question. So, for example, it would be reasonable to recruit a child with cerebral palsy into a study looking at management of pain in cerebral palsy because there is good reason to believe that conclusions from pain in other conditions should not be extrapolated to cerebral palsy. It would be much harder to argue that such a child be recruited into a study of management of leukaemia, because there is no plausible reason not to extrapolate data from groups of children who can choose to participate. I may have missed it, but it did not seem that point was made clearly in the existing document.

Hope this is helpful. I do realise that the current document addresses many of these points already.