

# Is research involving babies and children unethical?



Medical research involving children is important for the benefit of all children. It leads to innovations in healthcare that can substantially improve their health and quality of life



## Mother

“Babies need special protection as they are vulnerable and cannot safeguard their own interests like adults. If my child is ill and the research could help her then I would consider it. But as a mother my instinct is to protect my baby – I could not justify allowing her to be put at any risk if there is no direct benefit to her.”

## Paediatrician

“Babies are incredibly precious and parents and doctors are understandably very concerned that no harm should come to them. But research involving them is key to finding better and safer treatments for childhood diseases.”

## Ethics expert

“If research is to be permitted upon non-consenting children it is crucial that there are appropriate guidelines governing the selection of the children and the conduct of the research.”

*Ethical concerns regarding guidelines for the conduct of clinical research on children, SD Edwards and MJ McNamee 2005 31: 351-354 Journal of Medical Ethics*

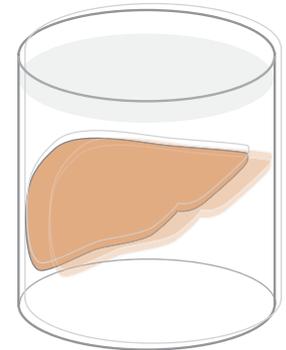
## Medical Research Council

“A parent/guardian’s informed consent is necessary for the involvement of babies in research. When a baby is seriously ill and a decision about treatment is required quickly, the pressure on parents is high and the difficulty of obtaining truly informed consent is recognised.”

*Medical Research Council Ethics Guide 2004: Medical research involving children*

Would you  
give consent  
for your body  
to go on  
display after  
you had died?

☞☞ 'The (Human Tissue) act makes consent the fundamental principle underpinning the storage and use of body parts, organs and tissue from the living or the deceased for specified health-related purposes and public display. ☞☞



## Pathologist

'People should not be exploited or degraded after death, and any procedures that help to prevent this are therefore appropriate.'

## Museum Curator

"Specimens from John Hunter's original museum are still used to illustrate new developments and their re-examination by modern methods often provides striking evidence of their value."

## Gunther von Hagens, Anatomist – Body Worlds Exhibition

"Display of human remains democratises anatomy, making us understand our bodies better. Studying diseased or damaged organs may also provide a benefit to public health."

## Public

"Both of my brothers died at a very early age. When I was a 14 year-old girl and watched as they were laid in a grave and buried, it was perfectly clear to me: 'I don't ever want to be buried!'"

# Should parents be able to genetically select their children as 'saviour siblings'?



In the UK it is now legal to select a tissue-matched embryo with IVF treatment (in vitro fertilisation), if a sibling has a serious or life-threatening illness. The UK's highest court has given the go ahead for the creation of "saviour siblings" to give umbilical cord, blood, or bone marrow to try to save the life of a brother or sister.

## Parents

"Our son was born with a condition called Fanconi's anaemia. His bone marrow does not produce sufficient numbers of red cells, white cells or platelets. He is now 7 years old and his blood counts are starting to fall significantly. He is becoming prone to bleeding episodes and recurrent infections. Any one of these episodes could prove fatal and he will need a bone marrow or stem cell transplant if he is to survive. If we could have another child using IVF (in vitro fertilisation), with embryo selection, to ensure the baby will be of the same tissue type as our son, cord blood harvested at the birth could provide the stem cells for the transplant he so desperately needs."

## Pathologist

"If cord blood banking does not go as planned, the "saviour sibling" may need to undergo an operation to donate bone marrow; as a small child they would have no right to refuse this. And what if the transplant in their sibling does not go well? Bone marrow transplants can be very risky procedures with a significant mortality risk. If the transplant fails, there might be psychological issues for the "saviour sibling" if they were unable to 'save' their brother or sister."

## Pressure Group

"To create another child as a transplant source could set a dangerous precedent for uses of this kind of technology. How will the baby feel, for example, when he discovers that he was brought into the world to supply 'spare parts' for his sibling?"

## Fertility Doctor

"I believe - subject to the current safeguards that already exist - pre-implantation tissue typing (IVF to create "saviour siblings") should be available throughout our NHS to all who need it; and that this would be entirely appropriate in a modern, civilised and caring society."