



Ethical issues in large-cohort research

Social relevance and distributed responsibilities

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Overview



1. Some concrete ethical issues in IDEFICS and I.Family
2. Wider ethical issue: the search for policy relevance and 'impact'

Some concrete issues



- Many difficulties of ‘informed consent’
 - Family involvement
 - Complex study – very hard to explain
 - Consent has to be broad (*not* fully informed)
- Storing children’s data/samples in long term – what to do when child reaches adulthood?
- Feedback – requests for genetic information
- Use of incentives for participation
- Sensitive questions – puberty, binge-eating...
- Innovative sub-study – fMRI with children

Resolving these issues



- In general, “ethics” does not speak with one voice
 - Need to balance different considerations
 - Appropriate solutions may vary across countries
- Sometimes the law imposes an answer...
 - Though that answer may differ quite starkly!
- Sometimes ethics committees impose an answer...

Neural correlates of healthy food viewing and food choice in tweens and their parents

I hereby confirm that I have read the information letter for participants <version-date>. I have had the opportunity to ask additional questions. These questions have been answered adequately. I have had enough time to think about participation.

I know that my participation is fully voluntary, and that I can withdraw my consent at any time, without having to give a reason.

I consent to be informed of chance findings that require medical intervention and I consent that in this case my general practitioner is notified.

I consent that my research data will be processed in the way described in the information letter.

I consent that my research data will be kept 15 years after the research.

I consent that my research data will be linked to my research data from the IDEFICS and I.Family studies.

I consent that my research data can be used for further analysis.

I would like to be informed of the results of this study on a group level [yes/no]

I consent to participation in the above mentioned study

.....

A wider ethical question



- Research ethics tends to emphasise protections and REC procedure
 - But many recent critiques of this narrow focus – e.g. problems of waste and distortion in research, questions about research priorities
 - We are also asking *a lot* of our participants – but to what end?
- The imperative to generate positive impact
 - Explicit challenge from various quarters: “What do your study results tell us to do?”
 - A fair question – but naïve!

Problems for policy impact

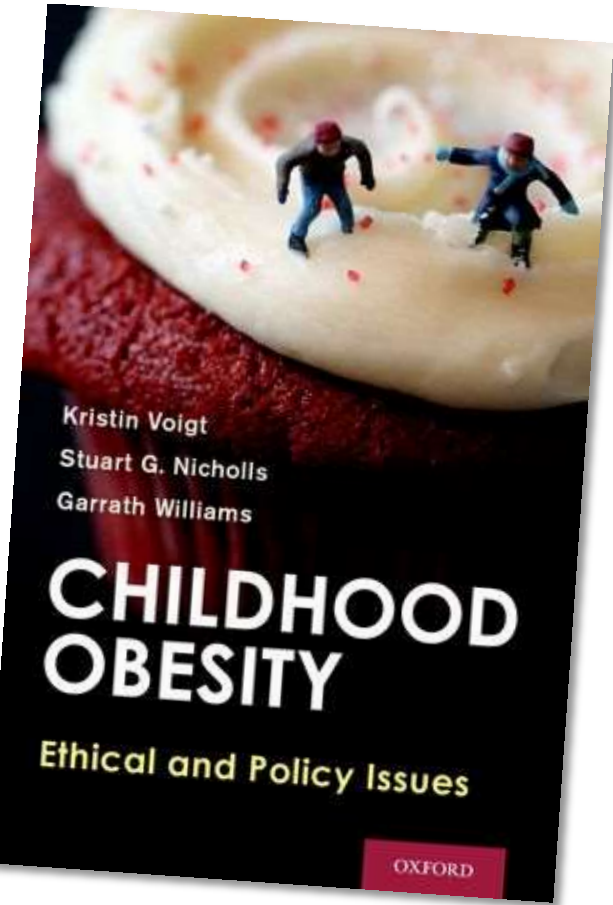


- Two sorts of complexity that block the challenge, “Tell us what to do!”
 1. Scientific complexity
 - We can only contribute to an emerging picture, not deliver unambiguous/incontestable results!
 - Unclear what social/economic changes would lead to changes in diet, activity, behaviour etc
 2. Complexity of policy making
 - Who will listen?
 - Who has the power to make changes?

Our approach



- Even clear evidence/prescriptions need complex & coordinated effort → social change
 - Cf. evidence on smoking
- Why?
 - Many actors with many preexisting priorities and responsibilities
 - People occupying different roles, institutions with complex responsibilities
 - Our priority – health – is never the whole story for them (nor should it be!)
 - It is rarely obvious who should do what – or what the costs/side-effects would be



So what can/should we contribute?



- We can explore different options for action – for individuals, parents, policy-makers
- Highlight possible benefits, costs and risks
- Look for ‘synergies’ with existing responsibilities & other priorities
 - → Minimising costs and risks
- But retain a certain modesty – there is room for different opinions & need for debate
 - Social/policy responses are a shared responsibility – and so is deciding what these should be

In sum



- Many detailed ethical issues for a study like ours
 - Not always clear or indisputable answers
- Many complex policy issues
 - However good our data and solid our findings, no clear or indisputable answers either!

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