More Involved Than What I Thought: Findings From an Informed Public Engagement About a Proposed Birth Cohort Study

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Overview

• Ethics engagement study
• Educational Video
• Findings
  - Pre existing knowledge and attitudes
  - Process participants/parents went through
  - Making a decision on child’s behalf
  - Things that matter to parents
  - Return of results
  - Parents value being well informed
Background

- Integral part of planning for Gen V
- Low public awareness about population research
- Partly informed by deliberative engagements and public perceptions research in US, Australia, Canada, UK
- What’s different about our study?
- Difference between Australian and US regulations?
- Main issue is ethics i.e. what regulations should be

(Lemke, Halverson, & Friedman Ross, 2012);
(C. Molster et al., 2011); (O'Doherty & and Burgess, 2009); (Cragg Ross Dawson, 2000).
Aims:

- To find out concerns, likely misunderstandings, possible negative reactions of potential participants
- Provide evidence base for designing aspects of the protocol e.g. recruitment and consent processes

Method:

- An informed engagement
- Focus groups based around an educational video.
Participants

- Source – Antenatal clinics at 2 hospitals (public and private), Barwon region in South-Eastern Australia.

- 3 focus groups – 17 participants – 14 F, 3 M
  - Most Australian born
  - Ancestry/ethnic origin mostly British/Irish and European.
    2 Asian. 1 Aboriginal/Torres Strait Islander.

- Small numbers an acceptable trade off for high quality, rich data
Purpose:

to generate thought and discussion, so that researchers can find out what participants think and want when well informed and what would reassure them

The video:

1. A balanced briefing about population research, biobanks, longitudinal and birth cohort studies, data linkage and the difference between medical care and research

2. Reasons why people do or do not participate

3. Experts providing explanations and reassurance on privacy, review of research and the policies and procedures researchers and research institutes adhere to.
Educational Video

Beth Wilson
Health Services Commissioner, Victoria
(1997-2012)
Findings: Pre-existing Knowledge and Attitudes

- Terminology – some but not all e.g. ‘biobank’, ‘cohort’
- Structures and processes to protect participants and information – most not familiar.
- Positive attitude to research, medical profession and research organisations
  ‘... I have a hundred percent trust ... I assume that what they’re doing is a hundred percent legit and that they’ve got my child’s best interests at heart’ [P2F]
- Less trust in commercial and government organisations
More Involved Than What I Thought

- Initially favourable but unconsidered:
  - ‘... I just thought “oh that’s fine, research is good”’ [PF1].

- Realisation that there is more involved:
  - ‘... there’s a lot more to it than just a simple sample’ [P14F]
  - ‘I just can’t believe what’s involved in it [laughter] I can see why you are having these sessions. You think I’ll just develop a study and off you go, but wow!’ [PF]

- More information and discussion restores positive view:
  - I’m pro. I’m for it. Yeah - it hasn’t - I’d be - look if I had to say yes or no right now I’d say yes ... [P17M]
Making a Decision on Child’s Behalf

More responsibility than deciding for self:

‘...you need to always know the expectation of – specifically your child. With you it’s even less. You don’t so much care what they want from you, but you do want to know what it is going to mean for your child ... you would want to know what you are committing your child to ...’ [P3F]

Could affect relationship with child:

‘... that would concern me because if the child knew that I’d given consent for all that private information of theirs to be shared, I would hate my mum for that ... you have no idea what sort of person they’re going to be, so how can you sign them on for something thinking of course they’d want to do that’ [P14F]
Things They Want to Know

Standard consent requirements:

• What’s involved?
• Safeguards to protect their information
• Opportunity to ask questions
• What could go wrong or complications?
• Policies and strategies for dealing with complications?
Things They Are Concerned About

- Anything that causes pain
- That my child’s name isn’t out there
- Information is being used for the purpose you said it would be
- Must be able to withdraw
- Don’t want to be judged as ‘bad’ parents when they answer questions about parenting
Recommendations: Things to Emphasize in Consent Process

- Data/samples will be used only for the purposes for which you have given consent
- Ask questions about anything you do not understand
- Ability to withdraw from the study (parent and child) and any limitations on withdrawal of samples/data.
- We understand the importance of the information that we have on your child and we have processes in place to keep it safe.
Return of Results: Wanted, But a Downside Recognized

‘... I can understand a study not having to release that, but I think yeah if you did a test that showed that my child had cancer cells and didn’t tell me I think that becomes a problem [P3F]

‘I’d feel annoyed, really that I was being so forthcoming with doing what I could and then things were withheld from me about my child. I would feel robbed’ [P17M]

• An area where public trust can be undermined and highlights confidentiality issues:
  ‘... if you’re able to single out my child and go Dear Mrs. So and so or whoever, your child Johnny is at risk of this, then it kind of makes it different from one of a hundred thousand kids [P10F]
Is there any point in providing information if parents’ views do not change?

“Yeah because it’s made it informed. Where you think about it and go ‘oh yeah, I’d do that’ but you now knowing all the information, it’s reinforcing - you go “yeah, no I definitely would do that. I can see the merit behind it. I think it’s a worthwhile -” [P17M]

- Parents value autonomy – being well informed and being given a choice
More Involved Than What They Thought

- People sometimes need to be given information to understand what information is material to their decisions.
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