

‘What do the public think of new non-invasive prenatal tests?: A Q-methodology study’

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Data presented from: *‘Is easier always better?: Public attitudes towards non-invasive prenatal testing’* ESRC core-funded project with Dr Hannah Farrimond and Dr Susan Kelly



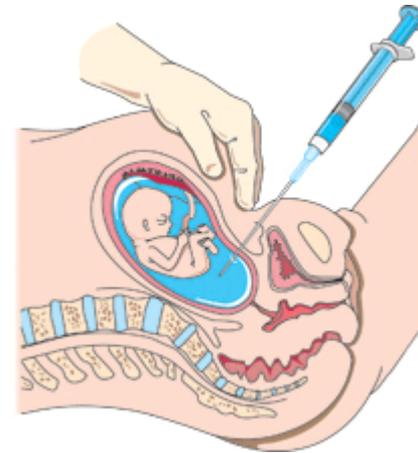
Outline of talk

I will present:

- The context and rationale for public attitudes research on NIPD
- The results of a Q-methodology study of public viewpoints of NIPD in a UK sample of men and women, focusing on consensus and difference
- Consider the utility of public attitudes research in relation to NIPD and ‘what next?’

The status quo

- Diagnostic testing for prenatal genetic conditions (e.g. Downs, Edwards, Patau syndrome) is currently 'invasive'
- Usually second step for 'high risk' individuals after risk screening (e.g. quadruple marker blood test/nuchal scan)
- After 15 weeks
- In this scenario, 'invasive' refer to the invasion of the amniotic cavity to obtain fluid (amniocentesis) or take placental material (chorionic villus sampling): infection, contamination or perforation
- = RISK OF MISCARRIAGE
- = DISTRESS OF 'INVASION'



Non-invasive prenatal technologies: the possibilities

NIPD= 'noninvasive prenatal
diagnosis'

Uses a sample of maternal blood,
or 'simple blood test' to
distinguish maternal and fetal
DNA (e.g. cffDNA), also whole
cell and RNA approaches

Key features:

Earlier (6-12 weeks)

Easier

Cost-effective

Risk reduction...



Why study public (s) attitudes?

- Studies to date conducted with 'high risk' pregnant women and female medical students, also parents with children with intellectual disabilities, none from 'wider publics'
- Important not to bypass public opinion and be led solely by 'technological imperative'
- Wider public operate to establish social norms and acceptability of new technological adoption; also have to live with consequences
- ESRC study 'Is easier always better?: investigating public attitudes towards non-invasive prenatal technologies' Jan 2009
- AIM: To identify a range of viewpoints on emerging NIPD technologies amongst a UK sample

Q-methodology study design

- 'Hybrid' qualitative/quantitative method
- Type of factor analytic technique (by-person) in which each person sorts statements on a topic. The Q-sorts are then factor analysed to identify shared accounts.
- Reason this method chosen? Ideal for investigating lay public attitudes on NIPD as little media coverage/knowledge of NIPD, so provides task to 'think through' the issues
- Response rate =73%
- Purposive sample: 71 participants, variation sought in gender, age (18-60), SES, ethnicity and religious affiliation, experience of parenting, genetic conditions and disability/life threatening illness

Demographic characteristics of participants

Variable	n=71
Gender	Male 24 (37%) Female 45 (63%)
Mean age	39.7 years (s.d. =11.46)
Socio-economic status	Higher 46 (65%) Lower 21 (29%) Unemployed/sick/disabled 4 (6%)
Ethnicity	White British 61 (86%) White Other 2 (2%) Mixed/Asian 4 (6%) British 4 (6%)
Children	Yes 52 (73%) No 19 (27%)
Experience of prenatal screening	Yes 41 (58%) No 30 (42%)
Experience of disability/life-limiting illness	Yes 33 (47%) No 38 (53%)
Experience of genetic conditions or testing	Yes 24 (34%) No 47 (66%)

The Q-sort process

- **Study approved** by HuSS Ethics Committee, University of Exeter
- **Designing the statements:** 157 statements in total created by both researchers, then condensed to 70. Covered current discourses towards science, disability in general, abortion, specific features of NIPD taken from research articles, policy documents, media articles, qualitative interviews
- **Doing the Q-sort:** Participants were asked to sort the statements from 'strongly disagree' (-6) to 'strongly agree' (+6) in a pattern in relation to each other to produce 'holistic viewpoint' on NIPD
- **Commenting on the statements:** They made open-ended written comments on key statements
- **Time-consuming:** Takes about an hour
- **Paid** £15 in Boots vouchers

Standard Q-sort grid

Figure 1: Ideal factor array for Factor One

<i>MOST DISAGREE</i>			?			<i>MOST AGREE</i>						
-6	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5	+6
34	45	37*	8	9	2	1	7	19	5	11	4*	33*
36*	53	38	15	41	6	3	29	22	16	42	24	46
	60*	49	21*	43	14	10	30	44	17	56	31	
		57	27	49	18	12	32	50	54	63		
			47	58	23	13	51	64	67			
				68	25	20	59	66				
				70	26	48	61	69				
					28	52	62					
						35	53	39				
							65					

*Indicates distinguishing items

Results

- **Factor analysis:** The sorts were factor analysed to see which sorts are similar at an above chance statistical level ($p < 0.01$) using PCQ Method software using varimax rotation
- **Results:** four factor model (explaining 48% of the variance) with each factor represent a shared 'discourse' or 'viewpoint'
- **Interpretive method:** Sorts which load onto each factor significantly are merged to create an 'ideal array'. The qualitative interpretation focuses on looking at the key statements in the 'ideal array' (e.g. which did they strongly agree or disagree with) coupled with the comments

Factor 1: NIPD as discrimination against the disabled

27 participants

- **1. Diversity is normal, valuable and beneficial to society**

41. Ultimately, it benefits society if there are fewer disabled children (-6)*

‘Society needs diversity and I don’t think it makes a difference how many disabled children are in the world.’ (Female, no children)

- **2. The experience of disability can be positive**

45. People underestimate the capacity of many disabled children to be happy (+6)*

‘I have a daughter who is disabled. Her life is very happy’
(Female, with 21 year old daughter who is ‘profoundly disabled’)

Factor 1 cont.

- **NIPD exacerbates existing discrimination and is eugenic**

39. NIPD is a form of discrimination against disabled people (+4)*

‘Of course this is discrimination. This testing is to weed out and destroy disabled people, it ISN’T about choice, it’s about destruction, as Hitler wanted’ (Female, three children one with severe autism)

- **NIPD as exemplar of a more selfish/materialistic society**

69. You can’t reduce a human being to their ‘worth’ in terms of money (+6)*

‘NIPD will result in a colder, more egoistic society’ (Female, one child)

Factor 2: NIPD as a positive clinical application

20 participants

- **Rejection of NIPD as discrimination vs disabled**

39. NIPD is a form of discrimination against disabled people (-5)

'Testing is not discriminatory- thoughtless people are' (female, two children)

- **Earlier, easier, less risky testing is good**

16. Pre-natal testing should be as easy as possible for the parents (+5)*

'I believe that non-invasive pre-natal testing will be a wonderful step forward for genetic testing in the future removing the danger of losing a healthy baby, and offering the opportunity of much earlier abortion' (female, two children)

Factor 2 cont.

- **Earlier testing = peace of mind**

26. Knowing about any genetic conditions as early as possible in pregnancy allows you to prepare (+4)

‘I can’t see how finding out the health of your unborn foetus can cause any more stress than spending 9 months not knowing’ (female, two children)

- **‘Knowledge is power’ but within clinically-led system**

29. These tests would make good genetic counselling all the more important (+4)

‘I feel that if more knowledge is made available, it is imperative that this is backed up by professional counseling and support networks. That is why I would be against these tests being made available on the internet or via routes that bypass doctors or hospitals’ (Female, one child and currently pregnant)

Factor 3: NIPD for severe disorders only

6 participants

- **Rejection of ‘picking and choosing’ your child**
 - **Fear of trivialization and routinization =‘high risk’ model**
8. New tests should only be used to find out about serious medical conditions (+6)*
9. I worry people will end up testing and having terminations for trivial things (+5)

‘This seems to be the start of the slippery slope of choosing your ‘designer baby’...I feel very strongly that these tests should only be used to screen for serious medical conditions and not for genetic predispositions to disease or for traits or characteristics’ (female, one child)

Factor 4: NIPD as parental choice

3 participants

- **‘Parental choice’ as key value**
 - **Happy for expansion of testing including for non-medical sex selection/paternity**
4. It’s up to parents to decide if they want to know the sex of their baby early on (+6)*
 6. It should always be up to the parents to decide whether to have NIPD or not (+5)

‘It should be the parents’ decision what tests to have and what they want to do with the results’ (female, currently pregnant)

Consensus

- **Rejection of compulsion/mandatory testing**

66. Parents shouldn't be able to opt out of NIPD. Having disabled children affects society as a whole (-4, -6, -5, -6)

‘Such measurement recalls Nazi procedures and should not be given thought’ (male, four children)

- **Concern about direct-to-consumer/commercial testing**

56. Parents should be able to have these tests directly without going through a hospital or doctor (-3, -5, -6, -4)

‘Would be a major problem in terms of interpreting results’ (female, three children)

These consensus statements form the boundaries of current societal limits around prenatal testing and NIPD for the public

Limitations of current study/ future research

- **Q-methodology:** useful tool to identify whole viewpoints, plus minority positions (e.g. Factor 4): represented in public inquiry
- **Not a representative sample:** can't determine prevalence of any one viewpoint in the population
- **Culturally bounded to UK:** different set of cultural discourses would result in different results
- **Future research:** comparisons with countries with significant sex-selection practices/different commercial structures, survey arising out of Q-methodology to assess prevalence of viewpoints



Broader questions

- What is the role of public attitude research? (e.g. facilitate participation in policy decision-making, find boundaries of social acceptability for clinical or regulatory decisions, reflect back evolving attitudes)
- How can we stimulate public debate and engagement around NIPD (and do we want to?)



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