Routinisation, choice and parental reflections on decisions to accept newborn bloodspot screening

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Overview

- Motivation
- Newborn bloodspot screening in the UK
- Data on parental experiences:
  - Interviews
  - Postal survey
- Summary and conclusion

Screening defined

"The systematic application of a test or inquiry, to identify ***individuals*** *at sufficient risk of a specific disorder to warrant further investigation or direct* ***preventive action****, amongst persons who have not sought medical attention on account of symptoms of that disorder."* (UK National Screening Committee, 2000)

Newborn bloodspot screening

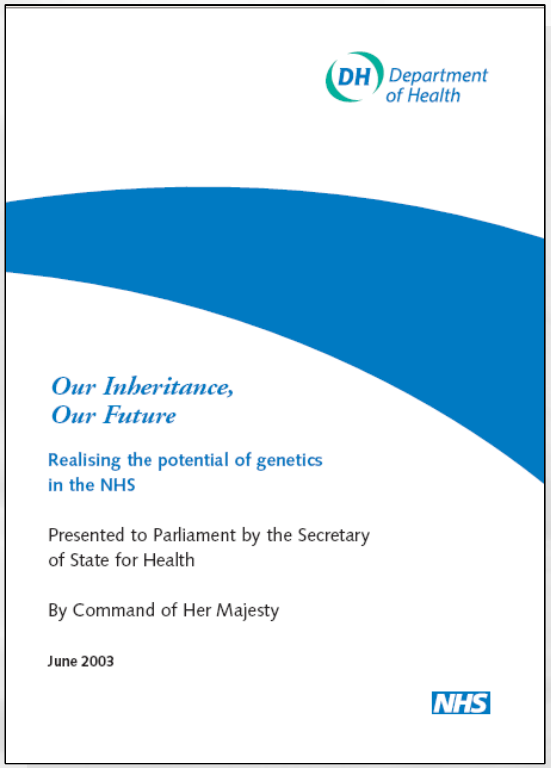
- Initial screening largely driven by phenylketonuria (PKU)
- PKU identified 1934; 1953 early detection lead to prevention
- 1961 – Bob Guthrie, 'agar diffusion microbial assay test'
- 1969 – UK national screening programme for PKU

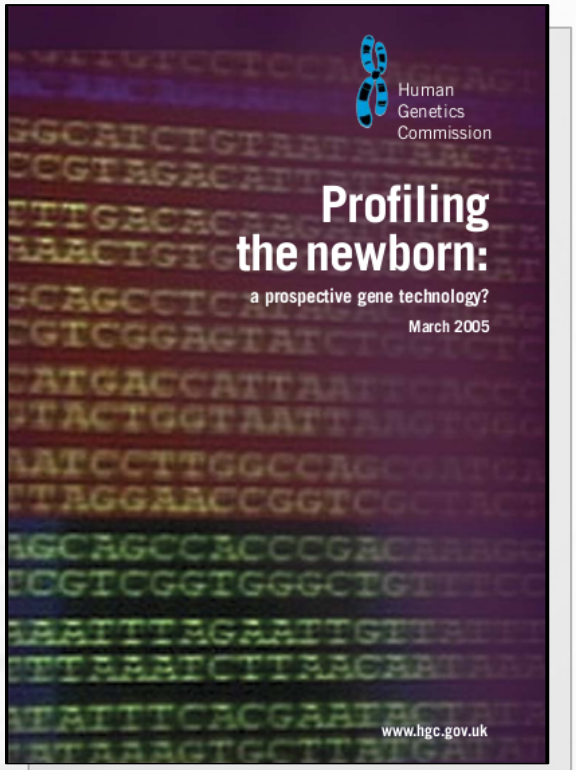
Motivation

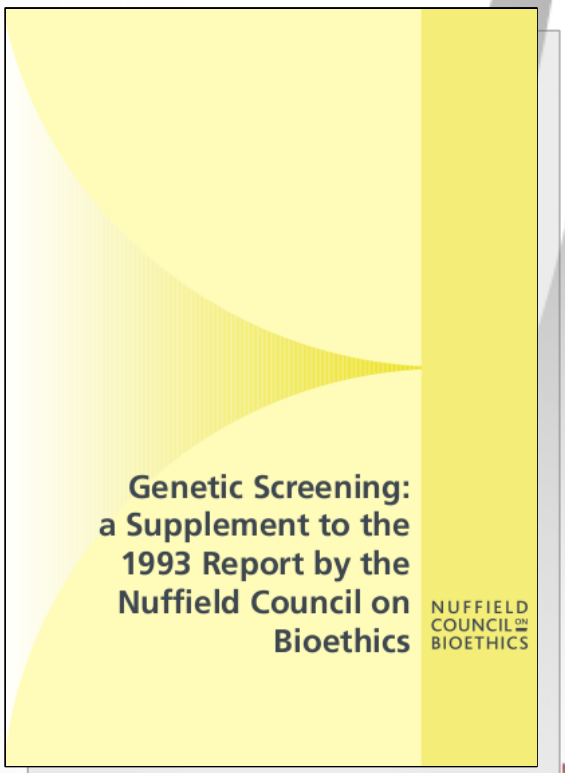
- Anecdotal evidence of routinisation
- Universally high uptake rates (Tymstra 1986, Parsons et al 2007, Detmar et al 2007)
- Increase in number of screened for conditions: ACMG in 2005 recommended 29 `core' conditions and 25 secondary
- Changing UK practice to include cystic fibrosis and MCADD

Motivation

- Increasing interest e.g. Henderson "Genetic mapping of babies by 2019 will transform preventive medicine." *The Times*, 2 February 2009







Motivation

- Determinants of uptake vary depending on screening test (Jepson et al., 2000) e.g. termination of pregnancy significant influence in prenatal screening (Potter et al., 2008)

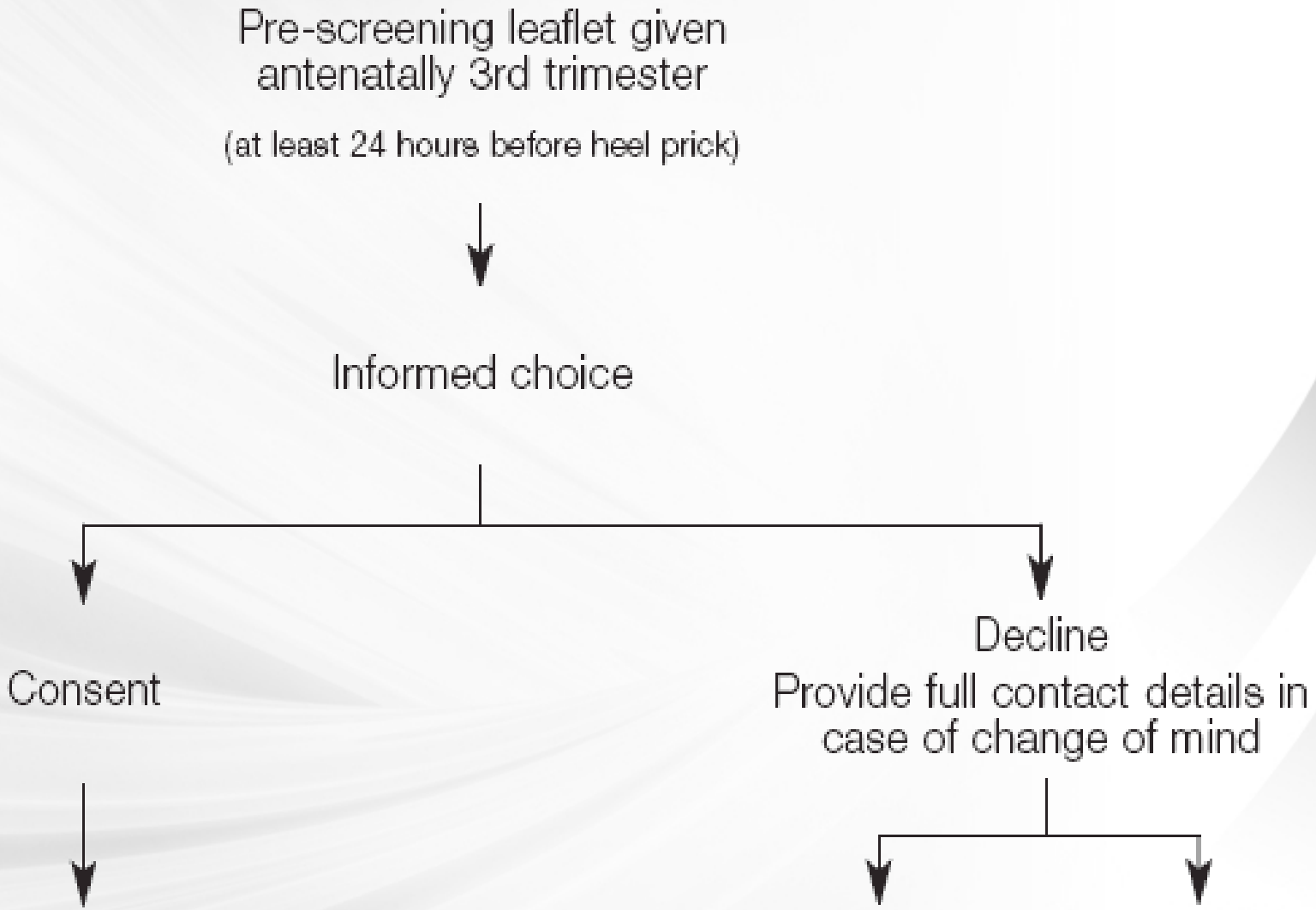
BUT

- "*...we found no studies which looked at parents' responses to the process or results of PKU screening and only a very small number looking at knowledge and attitudes to Guthrie testing in general"* (Green et al., 2004, p57).

Newborn bloodspot screening (UK)

- Conducted at 5-8 days of age
- Small amount of blood taken from the heel
- 5 conditions screened for in England:
  - phenylketonuria (PKU), congenital hypothyroidism (CHT), sickle cell diseases (SCD), cystic fibrosis (CF) and medium chain acyl-CoA, dehydrogenase deficiency (MCADD).
- Additional screen for Duchenne Muscular Dystrophy (DMD) in Wales

Newborn bloodspot screening (UK)



Newborn bloodspot screening (UK)

- Parents should be *"helped to make an informed choice"* (UK NSC 2000, p6)
- Midwife is to:

"Explain fully to parents and then record in the maternity record that newborn blood spot screening has been discussed and recommended, booklet given and consent sought. (UK Newborn Screening Programme Centre 2008, p2)

- 100% of babies to be offered screening

What do we mean by informed choice?

- Varying definitions of informed consent/choice (e.g. Gillon, 2001; Beauchamp and Childress, 2001; Dawson and Spencer, 2005)
- Core elements: Competency, Voluntary (uncoerced), Based on relevant information, Decision
- Each are necessary, but insufficient for informed consent

Why is informed choice important?

- A strong case in support of consent procedures is that they;

"[provide] reasonable assurance that a patient (research subject, tissue donor) has not been deceived or coerced." (O'Neill, 2003)

- On these grounds the voluntariness and the perceived choice are central to the ethical importance of informed choice/consent procedures

Aim

To explore how parents experience the informed consent process for newborn bloodspot screening (with particular attention paid to choice and voluntariness)

Methods

- Exploratory sequential mixed methods design (Creswell & Plano Clark, 2007)
- Phase I: Interviews
- Phase II: Postal survey
- Parents of children survey by Merseyside & Cheshire screening laboratory
- Excluded if child seriously ill or had subsequently died

Phase I: Interviews

- Purposive sample: accept vs decline (Suriadi et al., 2004); socio-economic status (Parsons et al., 2005)
- Identified through screening records, National Childbirth Trust (NCT) & Sure Start (< 3 years of age)
- Audio-recorded & transcribed
- Thematic analysis (Boyatzis, 1998) using Atlas.ti QDA software

Phase I: Interviews: Results

Item		Number (N=18)
Gender		
	Male	2
	Female	16
Parity		
	Primaparous	12
	Multiparous	6
Screening status		
	Accept	18
	Decline	0
Area profile (SES)		
	Low	2
	Medium	14
	High	2

Routinisation

- Largely experienced as routine, and conducted as part of postnatal care:

"They said they need to do some, something routine, I think I signed something, erm, and then, they said they needed to do a couple of routine tests..." SP

- Often perpetuated by inclusion with other postnatal checks – screening becomes perceived as routine (Pilnick, 2008)

"It was just, as I said, it was just one of those things that was all part of that, all of this, this big machine that happens as soon as you, as soon as you have a baby. You know […] triggering all these visits from people...its just, not like a tread mill but you realise that you are part of this, as I said, system." HP

"[...] you're getting that many things done, you just go yeah, yeah, yeah." JS

Dualistic representation: importance & insignificance

- Presentation: maximise uptake and minimise concern

"Erm ,[...] the way it's offered can throw people a little bit. If it's offered in a way that they're almost expecting the results to be negative […] then you're going to go along with it." LH

- This was counterbalanced with the importance placed on the heel prick by the midwife

"[...] so I do remember them saying erm […] well they must have said it was voluntary although I do think they do say that it is very, very recommended that you do have it." LM

Dualistic representation: importance & insignificance

- For some this was seen as a way of generating compliance, in part mitigated by the presentation of information

"You may have considered a whole suite of evidence in coming to a decision about what the best course is, but then when you come to sell that to people, you're not gonna try and take them through the entire decision-making process and show all the pros and cons and, necessarily in a balanced way. You've got, you've got the decision, you want people to comply with that so you might as well, err, present the benefits." SPW

- Manipulation?
- BUT no decision is free from influence e.g. family, social norms etc

Experience as a *fait accompli* (Parsons et al., 2007)

Constrained choice

- For some, a lack of time to make the decision inhibited an informed choice

"[...] you're not, you're not really given the information sort of one day and then they present you with something and say [...] now we'll leave the information with you and we'll come back tomorrow, because they would be coming back tomorrow anyway because they see you every day the first few days. They don't do that [...] the literally say, blllllr the test and right here's the needle and they're about to take the blood. So it's a very very quick process and you're not given any option to think about it." "LM

Constrained choice

- For others the issue was the timing, and this was particularly related to competence

"Because you don't get time to read things when you've got a new baby in the house. Erm, or if you do you just have a quick scan of it and just go yeah that's fine and don't think any more of it. Which I'm sure the majority of people would admit to" LH

- This was reflected in the may many parents talked about not having information prior to the birth of their child

Competence to choose

- Some mothers reflected on their emotional or biological state as impeding their decision-making

"[…] you're a little bit more subservient first time because the experience is so new, and the emotions are so new, that you sort of get carried along with it all, and it's not just the euphoria and everything, but it's just the whole, you're absolutely knackered, you're shell shocked" LH

- Preference for information provision pre-natally

Phase II: Survey

- Random sample (N=500)
- Mothers of children born in 2008
- Excluded if child had subsequently died
- 12 parents excluded as no longer at address
- 154 responses (response rate 32%)

Ability to make a choice

- Q. I felt I had enough time to make a decision about the heel prick
- Q. I felt I was too tired to make a decision about the heel prick
- Q. I was too emotional to make a decision about the heel prick
- Q. I did not feel able to make a decision about the heel prick

Availability of choice

- Q. It was expected that my child had the heel prick
- Q. The heel prick was presented as an optional test
- Q. I felt I had a choice to decline the test
- Q. I feel I have made an informed choice
- 5 point likert-type scale (Strongly Agree, Agree, Neither, Disagree, Disagree Strongly)

Respondent demographics

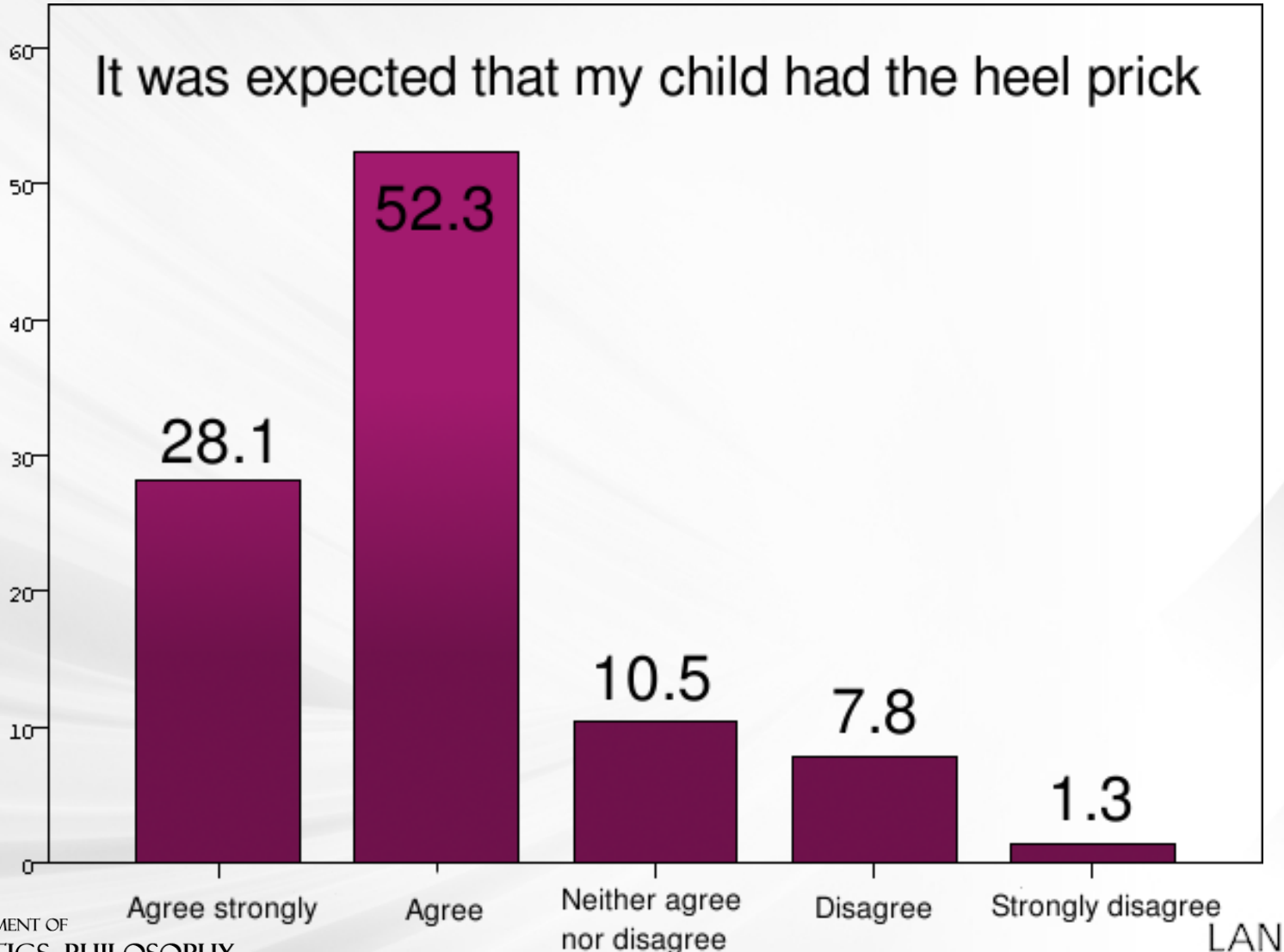
Item	Valid Number (%)
Age group	
Under 21	2 (1.3)
21-30	48 (31.2)
31-40	94 (61)
41-50	10 (6.5)
Number of children	
1	55 (35.7)
2	68 (44.2)
3	16 (10.4)
4	11 (7.1)
5 or more	4 (2.6)
Ethnicity	
White	147 (95.5)
Black Caribbean	1 (0.6)
Indian	2 (1.3)
Chinese	1 (0.6)
Other	3 (1.9)

Item	Valid Number (%)
Highest educational level	
School	31 (20.1)
College	32 (20.8)
Undergraduate	32 (20.8)
Postgraduate	20 (13.0)
Professional qualification	32 (20.8)
Other	4 (2.6)
Household income	
Less than £11500	16 (10.4)
£11501-18500	20 (13.0)
£18501-28000	18 (11.7)
£28001-41000	27 (17.5)
£41001-75000	44 (28.6)
Over £75000	21 (13.6)

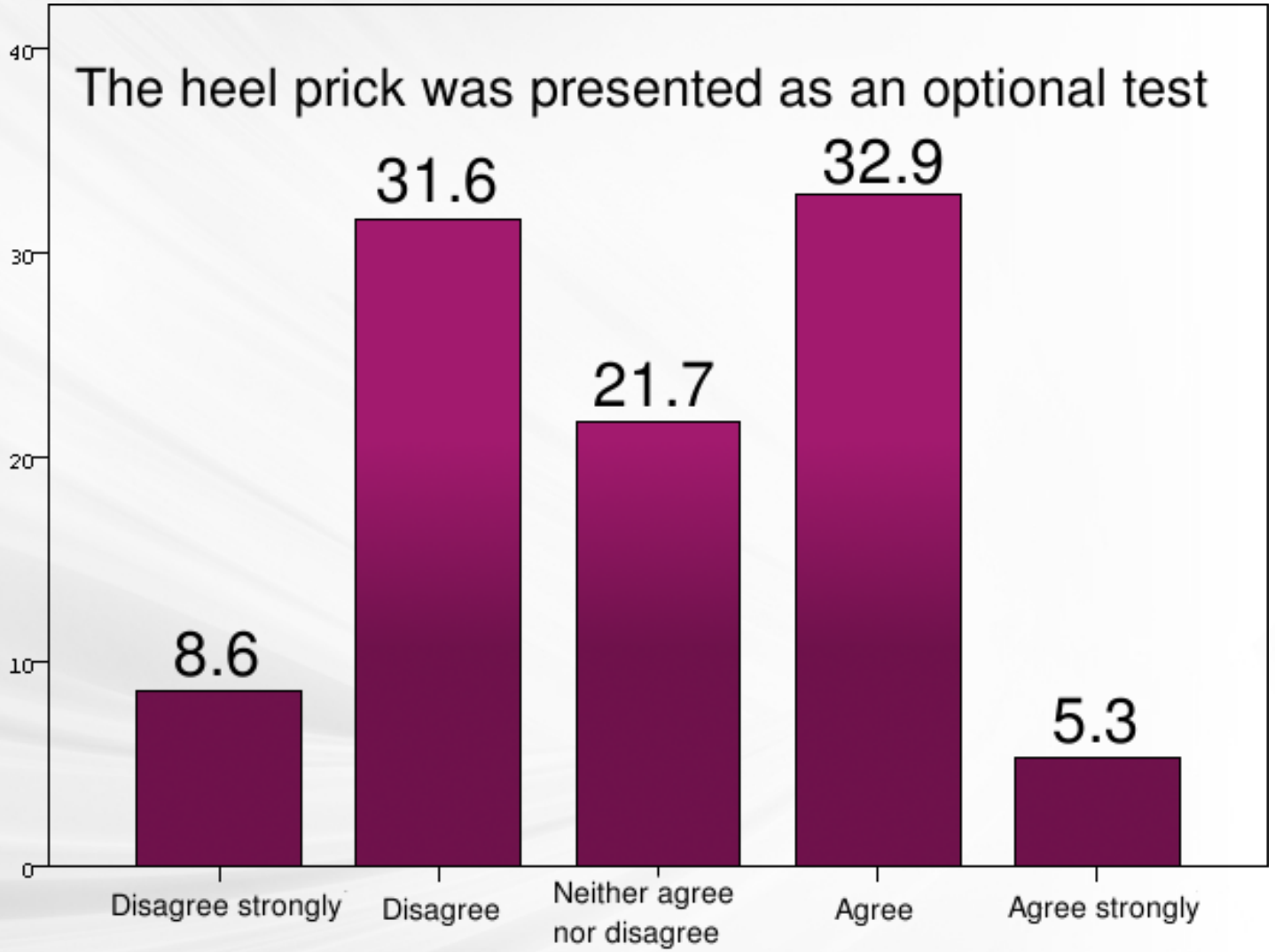
Perceptions of choice: ability

- Time to decide: 68.6% agreed to some degree, 16.7% disagreed to some degree
- Too tired: Almost three quarters (73%) disagreed with this statement to some degree
- Too emotional: Less than ten percent (9.8%) agreed with this statement to some degree
- Able to choose: 84.2% of parents felt able to make a decision (< 10% felt unable)

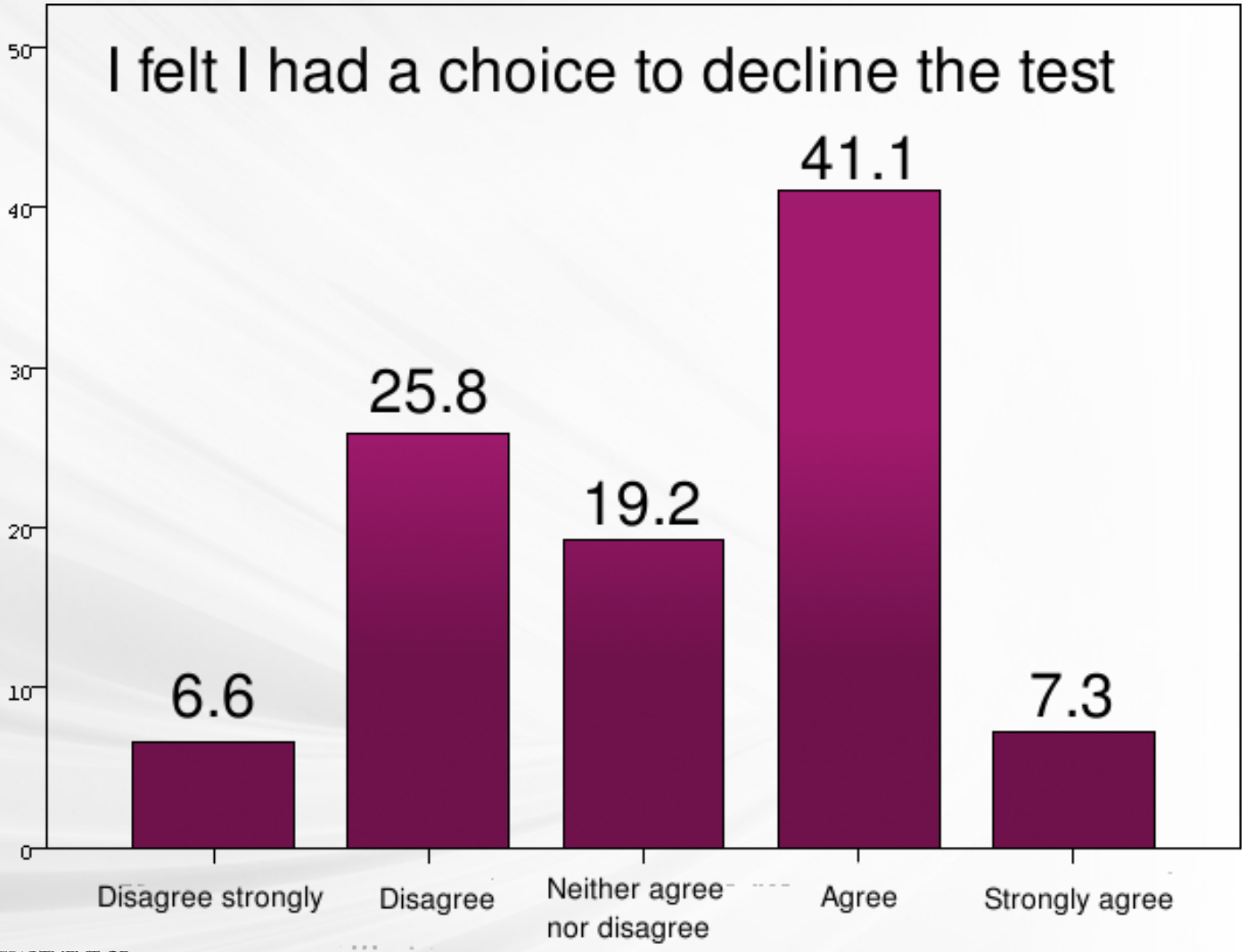
Perceptions of choice: availability



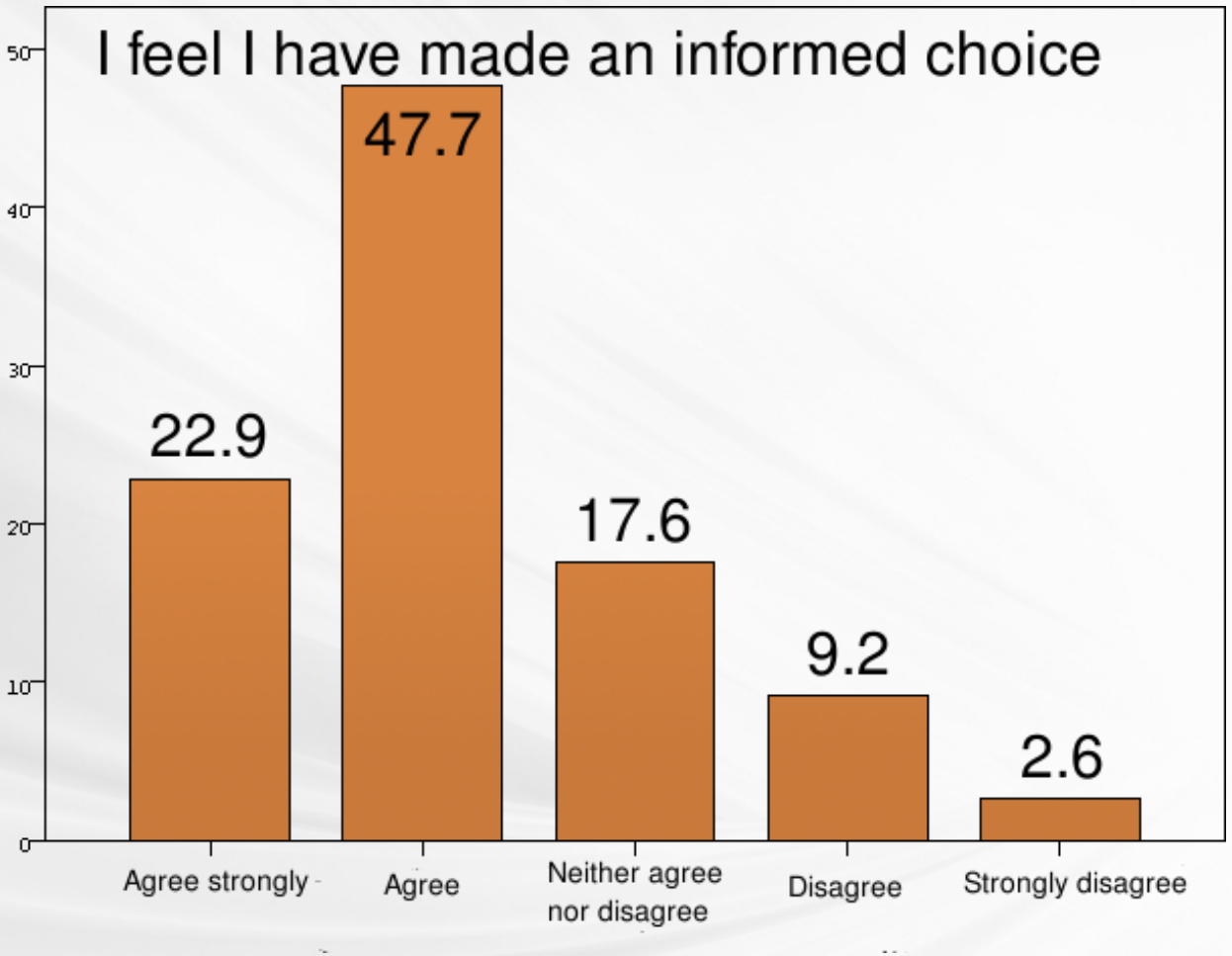
Perceptions of choice: availability



Perceptions of choice: availability



Perceptions of choice: availability



70.6% of respondents felt that they had made an informed choice to accept newborn screening

HOWEVER

A minority felt that they had not

Summary & conclusion(s)

- Availability of choice appears to be a greater issue than ability to make a choice
- Over 80% of parents felt that it was expected that their child had the heel prick
- 40% disagreed to some extent that the heel prick was presented as an optional test
- Over 30% of respondents felt that they did not have the choice to decline the test
- Over 10% did not feel that they had made an informed choice

Summary & conclusion(s)

- Parsons et al., (2005) 15% not aware optional, 4% felt they had no choice.
- McCourt (2006) `routine as choice' & `choice as routine'
- Stapleton, Kirkham & Thomas (2002) `Informed compliance'
- Presence of screening implies its worth, especially if seen as routine; “what is, must be best” (Porter & Macintyre, 1984)

Limitations

- All parents had accepted screening; cannot be extrapolated to those who decline
- Low response rate BUT comparable with other surveys in newborn screening (Mischler et al., 1998; Ciske et al., 2001; Davey et al., 2005).
- One region of England – practice may vary

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Additional information