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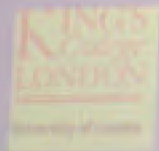
natal genetic screening
TA, Rome June 2005



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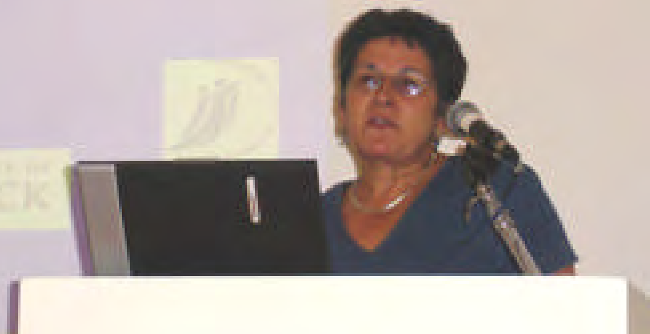
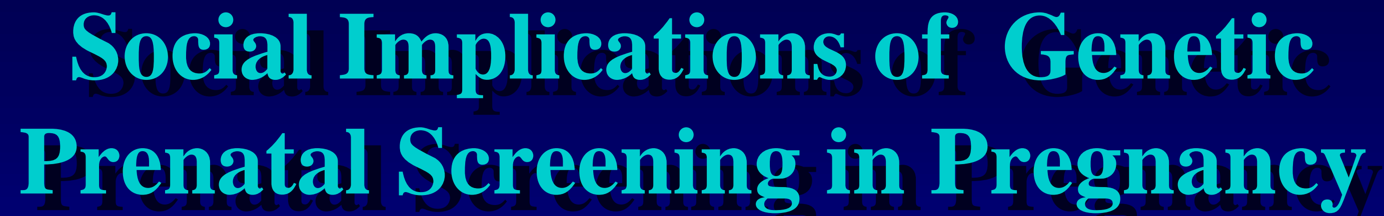


Multiple perspectives and mixed messages: narratives of evaluation of prenatal genetic screening

HTA, Rome June 2005



- **Professor G Hundt**
- Professor Jane Sandall
- Professor Bob Heyman
- Dr Kevin Spencer
- Dr Clare Williams
- (Laura Pitson)
- (Rachel Grellier)
- (Dr Maria Tsouroufli)
- Dr Pamela Lowe

- **University of Warwick**
- King's College, London
- City University, London
- B.H. & R. NHS Trust
- King's College, London
- (King's College, London)
- (University of Warwick)
- (University of Warwick)
- University of Warwick

Aims of study

- the impact of new screening technologies on the social management of pregnancy, service delivery and professional roles
- participants' broader responses to the new reproductive technologies, and views about routinisation of screening
- perceptions of self, the fetus, and the management of reproductive risk
- lay and professional understanding of complex information, and influences on decision-making.

‘The aim of screening for fetal anomalies is to identify specific structural malformations. This allows the parents to plan appropriate care during pregnancy and childbirth or for the parents to be offered other reproductive choices…. The woman’s right to accept or decline the test should be made clear’

Antenatal Care: Routine care for the healthy pregnant woman, NICE October 2003

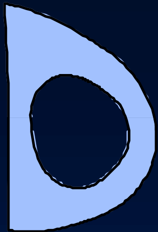
- 1st trimester NT&Biochem 10th – 13th week of pregnancy - results within 1 hour, CVS within 2 days, diagnostic test results 7-10 days after screening.
- 2nd trimester biochemistry 15- 16 - results within 3 days, amniocentesis within 3 days, test results 1-2 weeks

One Stop Clinics

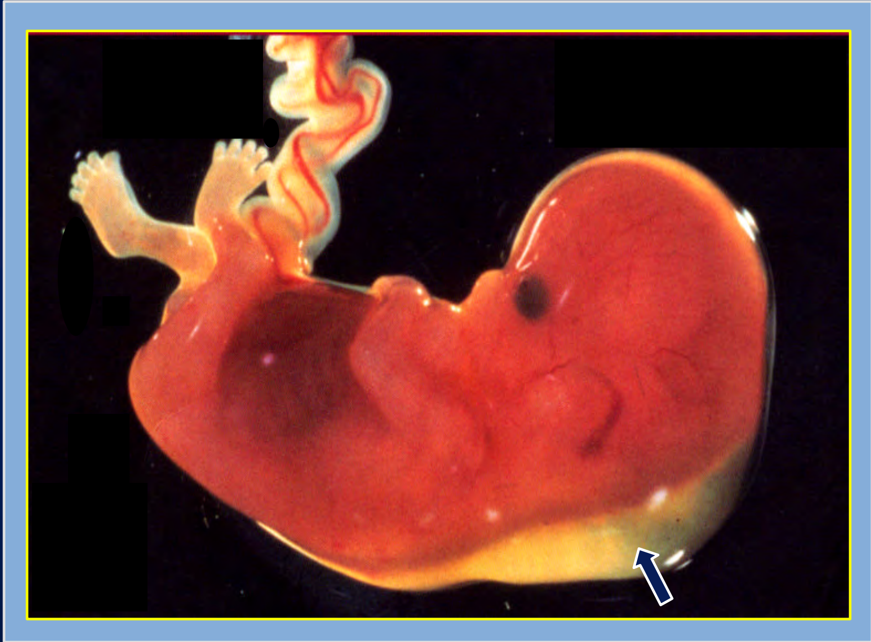
- One stop clinics have developed over the past decade in several clinical areas ranging from breast cancer screening, menopausal clinics,oncology assessment, cardiovascular risk clinics and one stop surgical clinics.
- These services all have in common the integration of a range of clinical and diagnostic services that allow for a better use of clinical time and improved diagnostic efficiency.
- They aim to maximise patient satisfaction by reducing the number of patient visits; minimising patient travel costs, anxiety and stress

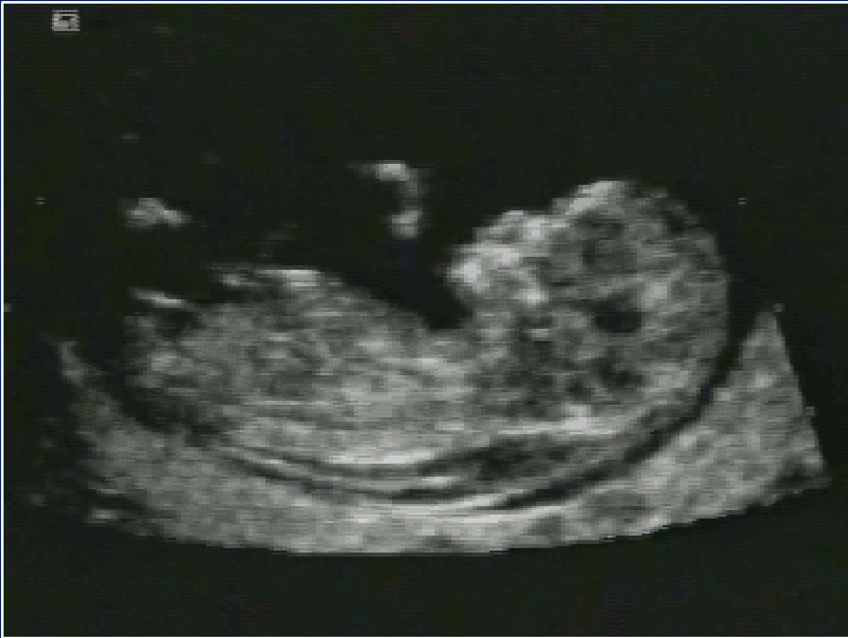
Point-of-Care screening for Chromosomal Anomalies in the First Trimester of Pregnancy. Spencer K, Clin Chem 2002; 48: 403-404

- Ultrasound markers of chromosomal anomalies - fetal nuchal translucency thickness at 10-13 weeks.
- Maternal serum Biochemical markers of chromosomal anomalies - free β–hCG & PAPP-A at 10-13 weeks.
- Development of new rapid assay technology for biochemical marker measurement leading to Point of Care testing.
- **DR 90% for 5% FPR. No of invasive procedures per case detected is 30**

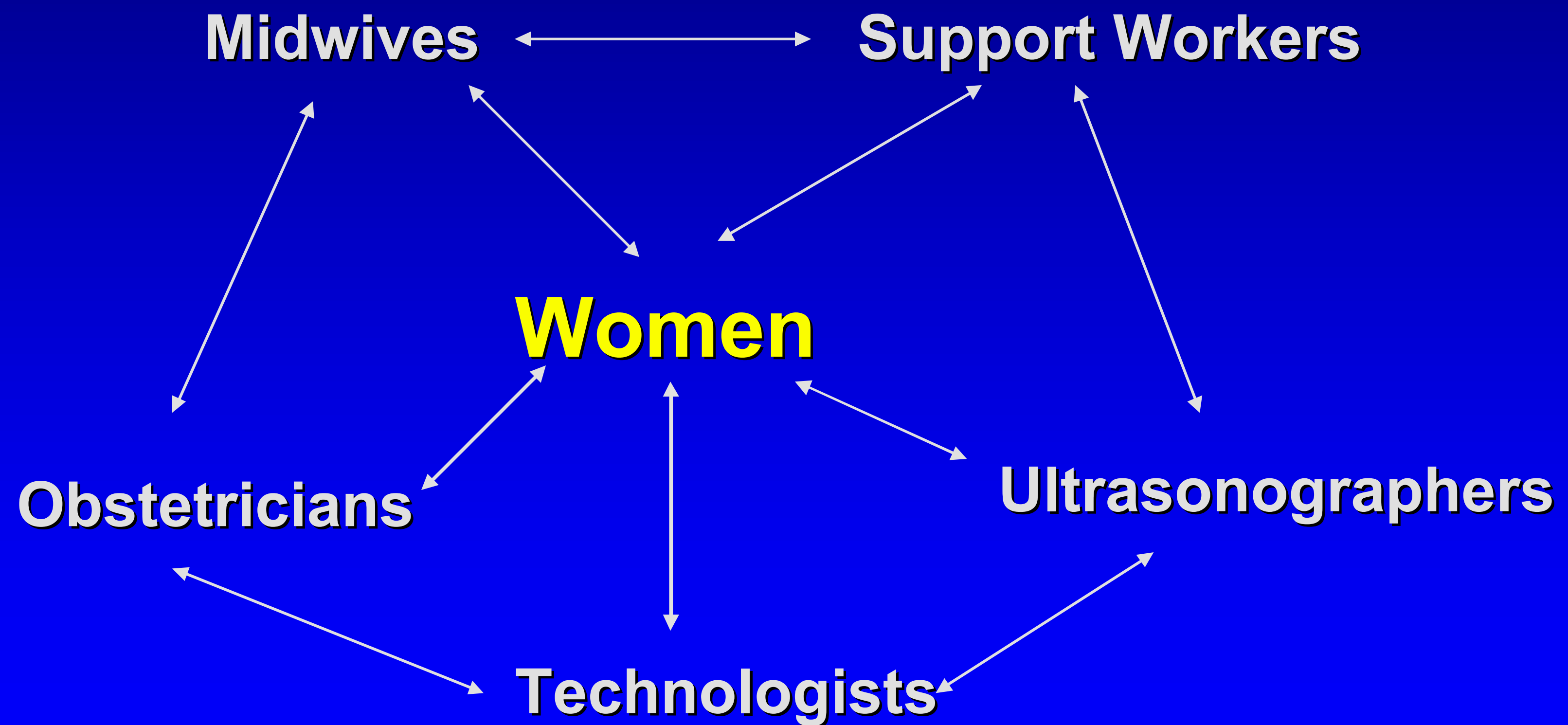


Nuchal translucency





Professional Interactions



Two sites

Innovative one stop – one of few NHS sites in UK

First trimester screening at a one-stop clinic at 12-13 weeks, NT ultrasound scan and blood test and result within 1 hour

Standard two stop

Second trimester screening at 15-20 weeks, result back within 1 week

Spencer et al (2003)BJOG,110:281-6.

Design

- Antenatal and postnatal survey of 1649 and 656 women respectively
- Observation of 45 clinic sessions in hospital and community
- Interviews with 24 health professionals and a cohort of 27 women and some partners on a range of screening pathways
- Analysis of 90 audio-taped consultations

Relevant social science concepts

- Medicalisation, Technology and the redefinition of personhood –
- Rites de passage
- jurisdictional boundaries between different professions
- Authoritative and experiential knowledge, paid and unpaid health workers
- Pedagogies of everyday life

Sonographers

- Sonographers have become key personnel
- They follow a protocol which sets out that they should explain the scan, demonstrate the outline of the foetus and limbs, answer questions and take a photo.

- Deciding where to draw the line in disclosure of the information they have from the scan,

- Concerned that women see the scan as a chance to see the baby and not as a screening tool.

Sonographers' dilemmas

- Sonographers do not always information on women's understanding of screening and of their position concerning informed consent for the scan

- They are aware of women's anxieties and try to handle the scan in a way that offers reassurance.

- ‘C gave an example of a woman who had come in very recently. On her notes the midwives had put that she had refused all screening. C then wanted to know why she had presented for a scan. It was because neither she or the midwife viewed it as screening.’ Fieldnotes 1-29/1/02

Role of phlebotomists

- Work within the clinic with individual women rather than with batches of blood
- Vital technical and social role with more autonomy
- Link between the midwives and sonographers

- Relations between sonographers, midwives and phelbotomists are ambiguous with unclear jurisdictional boundaries

Table 1

Views of women about ultrasound screening in 1st trimester pregnancy

Statement	Agree	Disagree
Reassured the baby was all right	95%	5%
Excited about having seen the baby	98%	2%
It made the pregnancy more real	91%	9%
I felt more attached to the baby	84%	16%
It made me see the baby as more of a person	87%	13%

- 'I am not sure what I was looking for out of the scan, other than definitely that a baby was there, that whatever they could see, everything was all right…' 1-15 multipara.
- Oh, it was good, it was brilliant. I was so happy. Thank God, I've come to this stage! Yes, it was good, it was good. Peace of mind, good.' 1-13 primapara

Going public

- ‘So, yes, seeing the heartbeat, I just thought, ‘ ‘that’s it, I am going to tell everybody now’’… I think that after 12 weeks, you run less of a risk of miscarriage and things like that… And so I know anything can happen but it definitely was a ‘ ‘right everything is okay, the scan is normal, I’m going to tell people’’ yes definitely’. 1-12ii

- Ultrasound becomes a social event which partners can attend
- Through the concretisation and visualisation of the foetus the pregnancy becomes real for everyone
- ‘I think it’s kind of made it a lot more real for my husband..., because he’s started talking a lot more about the baby now.’ 1-5ii

Partner's view

Yes I was trying to, as you tend to, well you do, you just stare at the screen and I was looking at it and,,,,,tried to be there and sort of held my wife's hand but again there is not a lot you can say at that point. If you open your mouth you put your foot in it basically…..You get a rush when you see it on the screen there….it's like when you feel the first kick, I mean it's great but the feelings for the child don't change…..It is a good feeling….it the only thing I can compare seeing the baby to…it's like remembering as a child when you scored a goal at football, it's the rush you get then. (partner interview, 01)

Ultrasound and the foetus

- The early utrasound scan becomes a landmark on the landscape of pregnancy.
- It makes the foetus a social being earlier, shown in photos in people's wallets or photo albums or on fridge doors.

- Some women refuse screening for measuring the nuchal fold or more rarely the scan.

Rejecting medicalisation

- ‘It’s not like I would scan and then I decided I wouldn’t. I think it was more that I was coming at it from the point of view that I wasn’t prepared to take any medical intervention for granted…. The thinking at the moment is that we will not scan for routine reasons, but you know, if I got knocked over by a bus…’ 1-14ii

Views of ultrasound (2)

Statement	Agree	Disagree
It's unusual for a scan to bring bad news	13%	87%
The main point of the scan is to get a picture of the baby	12%	88%
I was anxious about what the scan might show	89%	11%
Anxious about what the scan showed	46%	54%

Women’s understanding of the scan

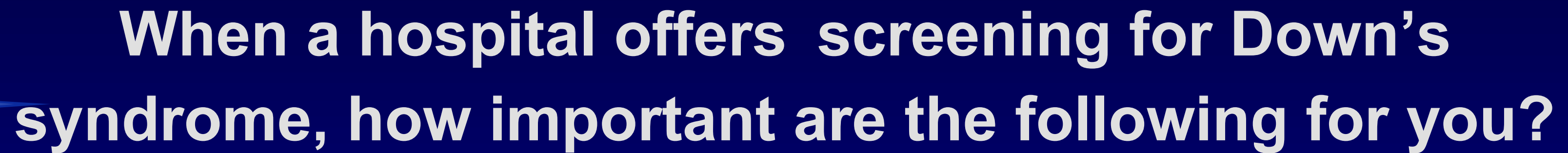
- “ I just thought ‘ ‘My God, if something was wrong after you’d seen it there on the screen’’ it made it so real. I just felt ‘ ‘Oh it must be absolutely horrendous if something was wrong’’. 1-8ii multipara

Views of women on ultrasound

Statement	Agree	Disagree
Scans are a necessary part of good antenatal care	99.6%	.2%
Having a scan is just behaving responsibly	79%	21%
It would be difficult to refuse all scans	73%	27%
Everyone has a scan so I went along with it	12%	74%

If you were pregnant again, what screening would you prefer?

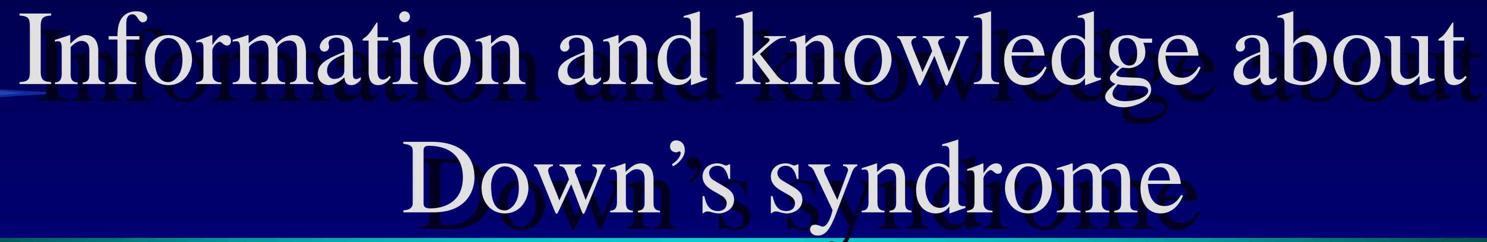
	One stop	**Standard**	**Total**
None	3	19	9
NT alone 12 weeks	20	17	19
Combined NT and blood at 12 weeks	88	66	79
Blood test 15-21 weeks	34	19	28



When a hospital offers screening for Down's syndrome, how important are the following for you?

% of women who say very important

	One stop	Standard	Total
Having time to discuss screening with HP before coming to clinic to have the test	54	67	59
Getting information before coming to the clinic	58	69	62
Having time to discuss with partner before coming to clinic	55	67	60
Having a scan as part of the screening test	76	70	74
Getting results back quickly	93	92	93
Knowing results early in pregnancy	92	86	90



Information and knowledge about Down's syndrome

- 80% of women reported receiving no information on Down's syndrome or the implications of having a child with this condition

Young women and those with lower education wanted more information

Screening Uptake in sites

	% One stop	% Standard	Total %	Sig
% Uptake N=733	95	63	83	P=0.000
% High risk N=20	3.2	5.7	3.9	
% Paid for screening N=137	2%	41%	16%	P=0.000

Accounts of community midwives

- At booking in Site 2 would tell women about a private option of 1st trimester screening
- Would make decisions about whether the woman had the resources to take this up prior to giving the information
- Two tier service

Fieldnotes from observation of bookings with community midwives

- ‘She said she did have the Devonshire Place leaflets (private service) and would mention it and offer a leaflet if she gauged that the woman might be interested.’ Site 2 community midwife - 9/04
- ‘Her steer away from private testing in general appeared from our conversation to be linked to her experience that women in this area had other financial priorities and needs. She saw it as a test for richer women but did not think it was actually a better test’ Site 2 community midwife 13/03

Summary

- Multiple perspectives and mixed messages from both health professionals and women elicited by mixed methods of evaluation
- Women as unpaid health workers know more than health professionals think from the pedagogies of everyday life including the clinic encounters
- IHTs have organisational, social and symbolic implications