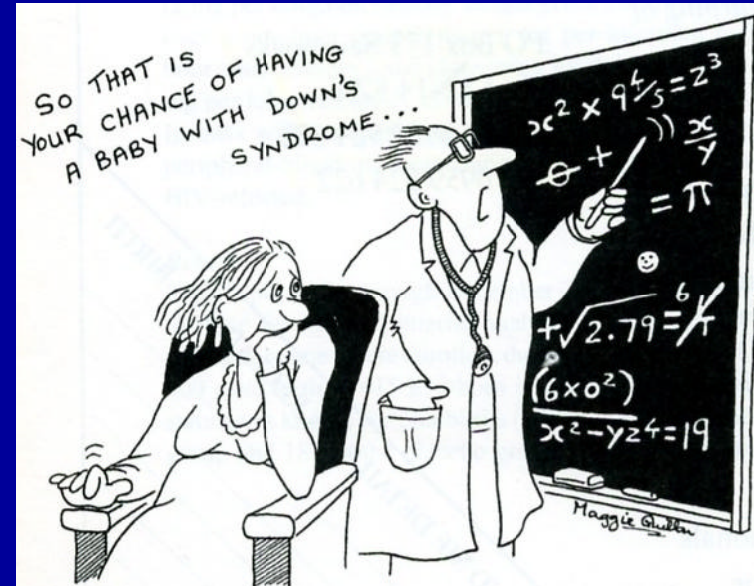


**Reflections on
Innovation, Routinisation
and Professional and
Patient
Experience in the Case of
Antenatal Screening**



**3rd Annual Meeting
Delivering and Experiencing Innovative Health Technologies: users perspectives
3rd November, Hamilton House, London**



Social and Organisational Implications Of One Stop First Trimester Prenatal Screening

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UK National Policy

‘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

Broader Issues

- Broader ethical and public policy implications (Kerr and Shakespeare 2002)
- Women's understanding of risk language (Heyman and Henriksen 2001)
- Routinisation and informed decision-making (Williams 2002)
- Raising anxiety (Hewison et al 2004)
- Inequalities of access (Sandall et al 2001)
- Whether/How women make selective use of technologies (Hundt 2001)

Project aims to Improve Understanding Of:

- Impact of new screening technologies on social management of pregnancy, service delivery and professional roles
- Participants broader responses to new reproductive technologies, and views about routinisation of screening
- Perceptions of self, the fetus, and of management of reproductive risk
- Lay and professional understanding of complex information, and influences on decision-making

Research Setting

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.

New issues arising from first trimester one-stop prenatal screening

Informed decision making

How much do women know already?

When do women decide to have screening?

Do women get enough/too much information early enough to make an informed decision to have screening?

What influence do family / health professionals have on decision making?

Routinisation

Does routinisation reduce inequalities in access for women who wish to have screening?

Do women feel under pressure?

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

Antenatal Questionnaire

1,649 women booked to give birth between 1/03 and 7/03 in 2 maternity hospitals in South East England sent opt out letter by NHS Trust

1,543 women still pregnant and who agreed to participate, received postal questionnaire between 23 and 30 weeks gestation from November 2002-May 2003

With three reminders, response rate = 64% N=993
(66% site 1 and 62% site 2)

478 women added written comments

Extra questionnaire sent to 128/136 women who screened positive and agreed (65% response rate)

Questionnaire Content

Demographic

Structure and content of antenatal care re screening

Information sources and quality

Decision making

Knowledge

Feelings about becoming pregnant and expectations
of motherhood

Attitudes to abortion

Fetal attachment

Anxiety (STAI)

General worries in pregnancy (Cambridge Worry Scale)

Sample Demographics

Age	%	Ethnicity	%	Education	%	Religion	%
<18	1	Asian	2	No quals	4	None	33
19-35	93	White	93	GCSE	45	Catholic	17
>40	6	African/ Caribbean	2	A level	20	Other Christian	42
Parity	%	Mixed	1	Degree	30	Jewish	2
Primipara	48	Chinese	1	Other	1	Other *	5
Multipara	52	Not answered	3			Not answered	6

*Buddhist, Hindu, Muslim, Sikh all under 2% N=

Informed decision making

Which of the following were discussed at booking? – “Prenatal screening to detect problems with the baby”

	Midwife	GP	Hospital Dr	HCA	Total
	%	%	%	%	%
Fully discussed	81	55	80	71	78
Not fully discussed	17	39	13	29	19
Can't remember	2	6	7	0	2

N=928

P=0.000

Informed decision making

How much information did you actually receive from doctors and midwives?

% reported not being discussed

Age	<21	22-39	>40	Total %
Options after screening test (n = 812) p=0.000	49	40	28	39
What it is like having a child with DS	71	85	77	84

Informed decision making

How did you feel about the amount of information you received at this appointment?

30% of women said it was too little

1% said it was too much

69% right amount

Said it was too little

45% women under age 21

62% women of mixed ethnicity, 48% Asian, 57% other ethnicity

37% women having first baby

38% women booked by GP, 54% women booked by HCA

Routinisation

Screening Practice

	% 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

Routinisation

When did you make up your mind whether or not you wanted to have screening for Down's syndrome?

	One stop	Standard	Total
Before pregnancy	22	32	26
Before screening offer	27	31	29
After screening offer	23	34	27
Never made up mind, but went along with offer	27	4	18

Routinisation

Have you found out about screening tests in any of the following ways?

	One stop	Standard	Total
Offered as part of routine care and it was assumed I would be having it	45%	6%	31%

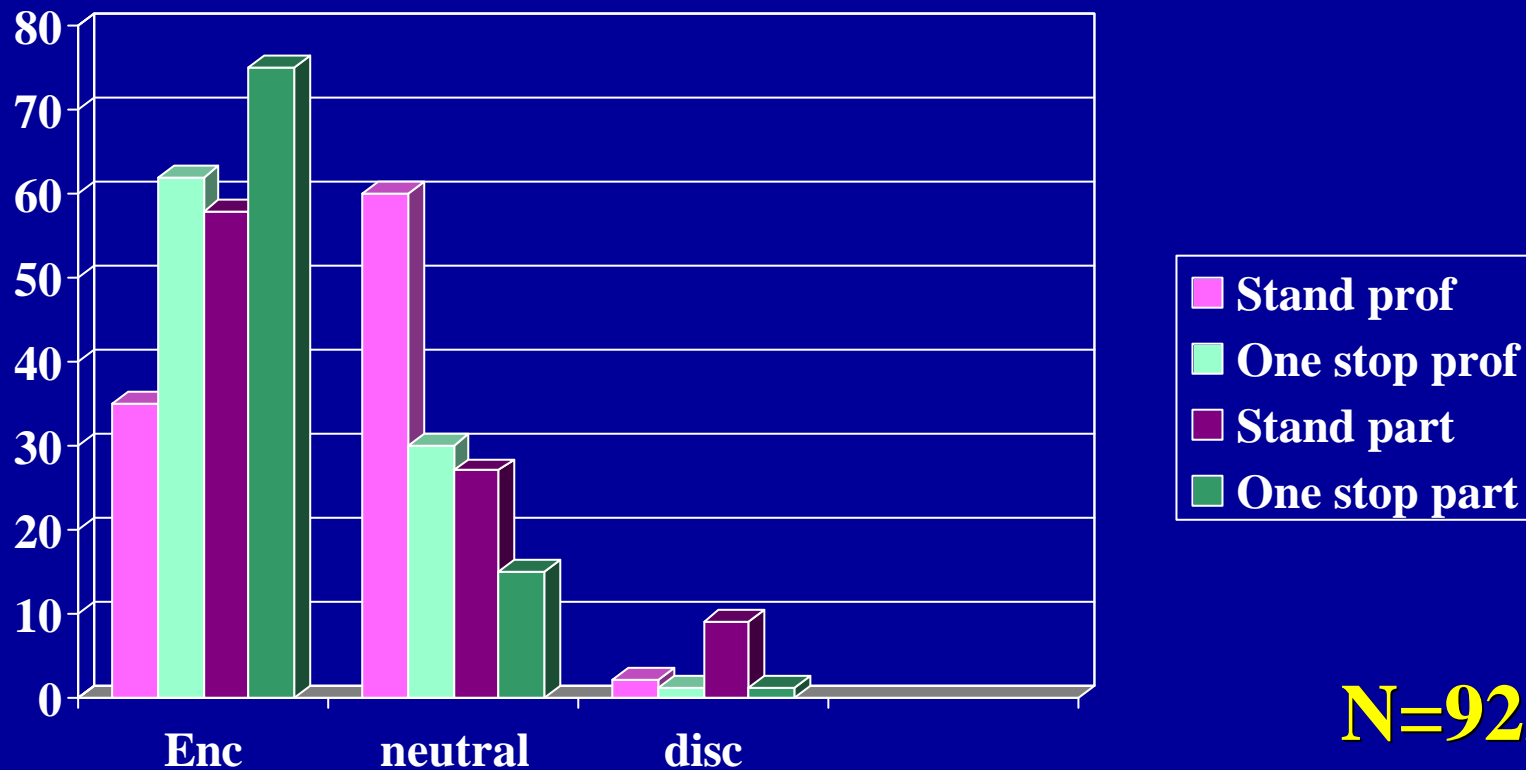
N=952 P=0.000

I found out for myself	7%	36%	18%
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N=952 P=0.000

Routinisation

What was the attitude of doctors and midwives (partners) to you having a screening test for Down's syndrome?



N=922

Women's views and wishes

People hold a wide range of views and there are no right and wrong answers. Please say how far you agree with the following statements.

% who strongly agree

	One stop	Standard	Total
All pregnant women should be offered screening for DS	73	51	65
Having screening is part of being a responsible mother	44	19	34

Women's views and wishes

If you were to get pregnant again, what screening if any would you prefer?

	Innovative	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

Women's views and wishes

When a hospital offers screening for Downs syndrome, how important are the following to you?

% of women who say very important

	Innovative	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

Women's views and wishes

Looking back, how much of a worry were these at the time?

% of women who a big worry/quite a worry

	Innovative	Standard	Total
Not being given enough information to decide	23	26	24
Getting screening results which are not 100% accurate	50	56	52
Having to decide before you were ready	17	23	21
Not having the opportunity to say 'no'	8	7	7

Conclusion

Informed decision making

Around 50% of all women had already made mind up about screening before their 1st appointment

Around 30% of women said they were not getting enough information DS as a condition and post screening options rarely discussed

Routinisation

Some evidence of routinisation in one stop site where uptake higher Staff, partners and womens' attitudes more favourable in one stop site Most women valued fast results, early screening and having an early scan

Substantial minority of women paying for screening in standard site and 75% of all women prepared to pay in next pregnancy

Policy and practice engagement

DIPEX module on antenatal screening

<http://www.dipex.org/>

NSC Professional training for informed choices in antenatal and neonatal screening

Multi-media training project

Quality standards for information giving in addition to technical aspects