INNOVATIVE HEALTH TECHNOLOGIES PROGRAMME





RESEARCH TEAM

Social and Organisational Implications of One Stop First Trimester Prenatal Screening

KEY FINDINGS

- Our study of the only NHS site in England offering combined first trimester screening for Downs syndrome in a one stop clinic has provided the opportunity to look at implications for women and health professionals before wide scale implementation in the UK. We wanted to explore:
- •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; women's and professionals' attitudes to and understandings of chromosomal risks, and their detection through screening
lay and professional understanding of complex information, and influences on decision-making.

- Uptake at 95% was significantly higher in the innovative site compared to 63% in the standard site. In the innovative site, 45% of women answered that they had been "offered a screening test as part of routine care and it was assumed I would be having it" compared to 6% in the standard site.
- This suggests a tendency to 'go with the flow' in a service where screening is integrated into routine antenatal care. For example, 67% of women in the innovative site, compared to 35% in the standard site reported professionals encouraged them to have screening.
- In the one-stop site, first trimester screening was tightly integrated into routine antenatal care, was popular with staff and most women, and uptake was very high. However, shifting antenatal screening to an 'opt out' rather than 'opt in' service may further erode issues such as informed choice and non-directive counselling which are already more rhetoric than reality.
- Most women valued early screening with fast results and liked the early scan. In the standard site that offered screening at around 15-16 weeks of pregnancy, 37% of women, paid to have first trimester screening. However, innovative first trimester screening technologies will continue the tradition of pregnant women acting as 'moral pioneers' in increasingly complex settings, and at a much earlier stage of pregnancy than previous screening policies necessitated.

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UK NICE guidelines state that the offer of screening for Down's syndrome is to become a *routine* part of antenatal care. Because of the greater level of accuracy required, screening will be moving to the first trimester using combined screening technologies. Our study of the *only NHS site* in England offering combined first trimester screening in a one stop clinic has provided the opportunity to look at implications for women and health professionals before wide scale implementation in the UK.

Routinisation, new technology and informed choice?

The development of prenatal screening technologies is controversial and politically charged, with ethical and public policy considerations. For such a policy to be considered ethical, non-directive 'counselling' and fully informed choice are essential, yet concerns have been raised as to whether these can exist. The tighter integration of screening into routine early antenatal care shifted screening from an 'opt-in' to an 'opt-out' service, with the resulting implications for informed choice.

Overall, 19% of women said screening was not fully discussed at booking, with significantly more women who were booked by GPs reporting this. A third of women reported that they would have liked more information than they were given, with significantly more women who: were under 21, having their first baby, or those who had no educational qualifications or degree level education reporting this. The information needs of these specific groups of women need greater attention, and will require different strategies. This includes a greater understanding of sources of information that women use apart from that provided by the NHS as around half of all women had made their decision concerning antenatal screening prior to any contact with the maternity services. Additionally the timing of information giving needs to be reviewed in the light of how antenatal services are staffed and delivered as screening moves into the first trimester.

When asked if they felt under pressure to have screening, 6% of all women said yes, and this was associated with factors such as: not having much time to decide; not being able to discuss tests as much as they wanted; and a positive attitude towards screening expressed by the health professional.

There were significant important differences between the two sites regarding processes for supporting an informed decision. Uptake was significantly higher in the innovative site at 95% compared to 63% in the standard site. In the innovative site, 27% of women reported that they never really made up their mind, but went along with what was offered, compared to 4 % in the standard site. Furthermore, 45% of women in the innovative site answered that they had been "offered a screening test as part of routine care and it was assumed I would be having it" compared to 6% in the standard site. This suggests a tendency to 'go with the flow' in a service where screening is integrated into early routine antenatal care.

Despite intended neutrality, the very act of offering Down's syndrome screening intrinsically puts forth the assertion that possession of this knowledge will be beneficial and empowering, and 67% of women in the innovative site, compared to 35% in the standard site reported professionals to be encouraging about screening. Changes in screening technology involve major system change in the organisation and delivery of early antenatal care. If an ethical screening policy is built on the concepts of informed choice and non-directiveness, then the implementation of routine first trimester screening may further erode such practices. which are often more rhetoric than reality.

Over 90% of women in both sites said fast results, and knowing results early in pregnancy were very important. In the site that offered standard screening at around 15-16 weeks of pregnancy, 37% of women, paid to have earlier screening which was associated with social advantage. In addition, 75% of all women were prepared to pay for 1st trimester screening in a future pregnancy if it was not available free. Although research has shown pregnant women can be active agents, rather than merely passive victims, there is also a simultaneous recognition that women's individual reproductive choices are made within the context of familial, social, cultural and economic constraints.

Moral Pioneers

In the area of antenatal screening, each technological advance, often seemingly minor in itself, may serve to shift the experiences of women in subtle but significant ways. These are difficult and complex aspects to tease out when exploring the experiences of women, particularly in our innovative site which simultaneously introduced a number of changes under the rubric of first trimester screening, with the potential for subtle and cumulative effects. Although many of these factors have been addressed by previous research, we argue that it is the novel combination of cumulative factors first trimester screening incorporates, plus related external developments, that necessitates pregnant women continuing to act as 'moral pioneers' in this setting.

In this site, almost the entire population of pregnant women opted for combined first trimester screening. It could be argued that this screening innovation, which has become highly routinised may serve to decisively consolidate the biomedical model of pregnancy, by foregrounding the possibility of fetal anomalies so early on in pregnancy. Others might argue that earlier, more accurate first trimester screening conveys advantages for women, particularly those who would wish to terminate an affected pregnancy. What does seem clear is that in the current UK policy climate, within which every woman must be offered the option of antenatal screening, innovative first trimester screening technologies firmly maintain the emphasis on the individualised risk model of pregnancy, whereby pregnant women themselves are enlisted in, and become responsible for 'their own government'.

It would therefore seem that whatever other implications they may have, innovative first trimester screening technologies will continue the tradition of pregnant women acting as 'moral pioneers' in increasingly complex settings, and at a much earlier stage of pregnancy than previous screening policies necessitated

Risk

Qualitative analysis documented pregnant women's diverse responses to the offer of screening, and to entering, living with and exiting from higher risk status. Some women reject screening in order to avoid the psychosocial and medical risks associated with higher risk status, or because they rule out pregnancy termination, and question the risk selection built implicitly into the provision of preventative systems for some health problems but not others. Women who screen at higher risk may challenge this designation by questioning the systemspecific probability used to separate them from the lower risk population. However, some experience distress even when they appreciate the precautionary basis on which their higher risk designation is based. They may find disengagement from higher risk status difficult after a diagnostic test has ruled out chromosomal anomalies.

Further research

The current debates are dominated by ideals of technical accuracy and individual choice. Further research is needed on the range of social relations that shape how, and what policies are put forward and the social shaping of women's choices.

There is little knowledge about the short and long term effects and implications of raised anxiety in women who are screened, and specifically in women who screen positive. There is little known about how the experience of screening earlier pregnancy

affects the ways women feel about pregnancy, birth and parenting, and whether this affects the decisions they make.

It is not known whether the increased routinisation and high uptake of screening makes it harder to opt out of, and whether women who choose not to accept may feel stigmatised.

About the Project

The project has provided the opportunity to look at the implications of an IHT prior to wide scale implementation in the UK. By looking at two sites we were able to explore issues that are common in any prenatal screening system and those that are unique to the innovative screening system. The innovative site provided a one-stop clinic for screening for Down's syndrome (the only NHS run clinic in England) where women can receive a result within a 1 hour clinic visit at 11-13 weeks gestation . In this clinic, the nuchal translucency measurement was combined with two first-trimester maternal serum markers, human chorionic gonadotrophin (hCG) and pregnancyassociated plasma protein A (PAPP-A) to calculate the risk of Down's syndrome, taking into account maternal age and gestational age. A second site was chosen of similar size and which serves a geographically and demographically similar population. The second site provided standard second trimester biochemical screening where results were returned within 1 week. Uptake was higher (95%) in the innovative site compared to the standard site (63%), which reflected the average uptake for London in 2002 of 64%. Thus in the innovative model of care, women were screened earlier in pregnancy, and got results back faster, with greater accuracy in a one-stop clinic visit, and greater routinisation of offer and process.

The study used a multi-method approach. Prospective, retrospective and crosssectional data, both qualitative and quantitative, were collected over a three year period from 2001 to 2004 the bulk in 2002 to 2003. Findings are based on data drawn from an antenatal and postnatal survey of 992 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 p at h w a y s and 90 a u d i o - t a p e d consultations.

The findings have been disseminated in a range of ways through conference presentations, policy briefings, maternity consumer newsletters, and academic and professional journals. In addition a performance has been developed from the research findings through funding from the Wellcome Trust as an additional way to reach to a range of audiences the main issues raised by this research.

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