Primary Health Care Research and Development 2000; **1**: 29–38

Antenatal screening in the community: the views and experience of women in one general practice

Jill E. Thistlethwaite Academic Department of General Practice, University of Leeds, Leeds and General Practitioner, Hebden Bridge Group Practice, West Yorkshire and **Joanne Jordan** Department of Sociology/Social Policy, University of Ulster, Newtownabbey, Northern Ireland

The publication of the Department of Health's 1993 report *Changing Childbirth* has prompted major changes in the organization of maternity care, with an emphasis on returning antenatal care to the community. Serum screening for Down's syndrome (triple test) is usually carried out and followed up in secondary care, and work relating to the psychosocial effects of the test has been hospital-based. The aims of this study were to examine the views of women regarding the process and effects of delivering the test as part of routine general practice-based antenatal care, with a view to considering how this care might be most appropriately managed. We sent a questionnaire to all women registered with a fundholding practice who were offered the triple test between 1992 and 1997. The main outcome measures were satisfaction with the way in which the test was offered, what women understood by positive/negative results, why some women declined the test, and satisfaction with obtaining results/follow-up. The response rate was 60.7%. The majority of women were satisfied with the way in which the test was discussed, but there was ambivalence with regard to the procedure for receiving results, including the counselling offered. Confusion over the meaning of the results (particularly negative results) was apparent. The test caused anxiety in many women. The need for continuity of advice and support when women are subsequently referred to secondary care for further tests was highlighted. The majority of women wish the test to be available for all. The conclusion we draw is that no abnormalities have been detected during the study period, raising questions about cost-effectiveness. However, the majority of women view the test as a means of making informed decisions about their pregnancies. Although limited to one practice, the issues associated with a broad range of aspects of care identified through an analysis of the experience both of women declining the test and those accepting it provide important insights into the practicalities of delivering antenatal screening tests in primary care.

Key words: antenatal screening; community-based maternity care; triple test

Introduction

Over the past decade, serum screening for Down's syndrome has been increasing in the UK (Cuckle *et al*., 1995), with the triple test being the most commonly used form of screening in the NHS (Wald *et al*., 1996). Initially the test (which also screens for Edward's syndrome and spina bifida) was only available to women over the age of 34 years, on account of their increased risk of carrying an affected fetus (Mutton *et al*., 1998). However, as the majority of Down's syndrome children are born to women under the age of 35 years (Wald

Address for correspondence: Dr J.E. Thistlethwaite, Academic Department of General Practice, University of Leeds, 20 Hyde Terrace, Leeds LS2 9LN, UK.

1463-4236(2000)PC005OA

et al., 1988), some health authorities now offer the test to all pregnant women.

The test is typically performed at around the fifteenth week of pregnancy, and test results are based on the mathematical combination of maternal and gestational age plus three serum markers to derive a risk estimate representing the probability that the fetus has Down's syndrome. The test identifies around 60% of Down's syndrome pregnancies, and produces both false-positive (*c*. 5%) and false-negative (*c*. 5%) results (Wald *et al*., 1998). If the derived risk is higher than some prespecified level, typically 1 in 200–250 (screen positive), diagnostic testing is offered.

Given the complex nature of the test, as well as the fact that results are only ever probabilistic, health professionals face considerable challenges in providing appropriate information, advice and support, while women may be confronted with the need to make difficult and often agonizing decisions ((Hewison, 1996). Thus the need to address the social and psychological consequences of offering the test, particularly in relation to the provisioning of counselling, has been highlighted (Wald *et al*., 1997b). The limited research conducted to date has drawn attention to both practical and emotional issues, including the concerns of health professionals over a lack of skills to provide appropriate counselling, and the anxieties of women who are often required to make decisions on the basis of limited information and support (Marteau *et al*., 1992a; Smith *et al*., 1994).

The publication of *Changing Childbirth* (Department of Health, 1993) has prompted major changes in the organization of maternity care. In particular, there has been considerable momentum behind the return of antenatal care to the local community. In relation to screening for fetal abnormalities, the report highlights the need for proper counselling to be provided, and recommends that providers review current arrangements. If primary care is to become the focus of maternity care, whether the lead role is to be assumed by midwives, general practitioners or both (Smith, 1996), then there is a need to consider how such care, including arrangements for antenatal screening, might best be delivered.

This study focuses on the point where the two developments outlined above converge – that is, on the delivery of the triple test in a primary care setting. Based in one general practice, the research addresses both practice-specific arrangements for care and a range of issues concerned with the delivery of community-based antenatal screening. We report here on selected results from the first part of the study, which concentrates on the views and experiences of those women to whom the triple test had been offered.

Background

The practice has offered the triple test to all pregnant women irrespective of age since June 1992. All members of the primary care team involved in test delivery (nine doctors and community midwives) are expected to follow a protocol which includes guidance on care and which acts as a mechanism for recording aspects of the care provided (see Box 1). When the triple test was first introduced, little information was available regarding appropriate pre- and post-test counselling. Consequently, although the developed protocol provides for the processing of the triple test, this does not include advice on appropriate counselling.

Method

We used computer records to generate the details of women offered the test on one or more occasions during the period June 1992 to March 1997. The questionnaire was piloted on 30 of these 610 women. We obtained a 50% response rate, with no changes being made to the original questionnaire (see Box 2). The remaining 580 women were subsequently sent the questionnaire together with a covering letter explaining the purpose of the study. Two months later, all nonresponders were sent a reminder letter and another copy of the questionnaire. Using the Statistical Package for the Social Sciences (SPSS), descriptive analysis generated percentage ratings for all specified variables.

Results

We obtained a response rate of 60.7% (352 out of 580 questionnaires returned). The total number of triple tests taken between June 1992 and March 1997 was 645. The number of women who had had at least one triple test was 474, of whom 264 individuals (55.6%) responded to the question-

Box 1 Triple test protocol

- GP first discusses triple test when woman presents in surgery to confirm or report pregnancy (usually at 6–8 weeks). Leaflet on test (provided by the Antenatal Screening Service) is given to the patient.
- GPU patients are booked by midwife at first clinic appointment or at home (since 1997). Triple test is discussed.
- Shared-care patients are booked at hospital; test may be discussed.
- Triple test is performed between 15 and 17 weeks' gestation by midwife or GP. Whether test is taken or declined is recorded on computer. Result is available within 1 week if negative, or 3 days if positive.
- *Screen-negative result*: result is discussed with the patient at their next clinic appointment.
- *Screen-positive result*: the patient is contacted by telephone or home visit if necessary. Appointment for amniocentesis is made at the hospital if the patient wishes.
- Amniocentesis result is available after 3 weeks, and is given to the patient at her hospital appointment.

naire. In total, 126 women had declined one or more triple tests, of whom 83 (65.9%) responded to the questionnaire. Ten women had taken the test under hospital care, of whom five (50%) responded. Thus the returned questionnaires were representative of the experiences of the total practice population. There were no Down's pregnancies during this time.

The results obtained from Sections 1 to 6 are shown in Tables 1 to 6.

Main findings

Overall, the majority of women were happy with the way in which the test was offered and discussed with them. The principal reasons for satisfaction were that the explanation was comprehensive and/or that the member of staff concerned was supportive of the woman's questions and concerns. For the smaller proportion of women who were dissatisfied, this was mainly due to a lack of explanation, particularly about the diagnostic capability of the test. A recurring theme was that a number of women in each category felt that practice staff and/or the leaflet were biased towards women having the test. Here, comments to the effect that the triple test was presented as 'just another test' are pertinent.

The other area in which dissatisfaction was apparent was the system for giving women the results of the test. Some women stated that they had been unsure of the procedure. Many felt that all results, not just screen positive, should be given to women as soon as they were available. A wish was expressed that all results should be given in person and only by qualified staff, not by receptionists.

Section 1 (Table 1)

There was a lack of knowledge about the triple test prior to it being offered in the practice. No clear pattern to understanding emerged among those women who claimed to have knowledge of the test. For example, the single largest group ($n = 33$) associated it with the identification of Down's syndrome alone, while only three women were aware that it was a method of screening for Down's and Edward's syndromes as well as for spina bifida.

Most women who stated that the practice had supplied written information found this to be useful, as it aided informed decision making (in that it could be read on repeated occasions) ($n = 48$), and it provided detailed information on the test independent of that given by practice staff ($n = 65$). The main reason cited by those women who did not find the leaflet useful related to the confusing, incomplete and/or simplistic nature of the information provided ($n = 11$).

The majority of women stated that they understood what it meant to have a positive and negative test result, with most clearly appreciating that the result provides a statistical probability (as opposed

Box 2 Questionnaire

- Section 1: about the triple test
  To be answered by all women.
  Questions on previous knowledge of test; when and by whom test was first discussed; whether happy with the discussion; whether written information was provided; what was understood by positive/negative test result.

- Section 2: declining the triple test
  To be answered by women who declined one or more tests.
  Questions on why they decided not to have the test; whether they were happy with this decision; whether staff gave sufficient information and advice.

- Section 3: a negative triple test result
  To be answered by women who had one or more screen-negative tests.
  Questions on why they decided to have the test; whether they were happy with this decision; whether staff gave sufficient information and advice; whether staff told them how the results would be obtained; whether they were satisfied with how the result was obtained and its explanation.

- Section 4: a positive triple test result
  To be answered by women who had one or more screen-positive tests.
  Questions on why they decided to have the test; whether they were happy with this decision; whether staff gave sufficient information and advice; whether staff told them how the results would be obtained; whether they were satisfied with how the result was obtained and its explanation; whether staff provided information about what would happen next.

- Section 5: the amniocentesis
  To be answered by women who had to decide whether to have an amniocentesis.
  Questions on whether they had an amniocentesis and what their reasons were for this decision; whether they were told how they would receive the result; whether they were satisfied with the explanation of the result.

- Section 6: the triple test in general
  To be answered by all women.
  Questions on whether they had anything else to say about the antenatal test; whether all women should be offered the test; whether they would be prepared to be interviewed about antenatal care in future.

to a definitive answer). Although some of the details of understanding among this group are open to question (for example, that a positive result indicated a *high* risk of abnormality), they were all making the same basic and essential distinction between diagnostic and nondiagnostic testing, and interpreting positive and negative results in the appropriate direction. A minority of women continued either to perceive the triple test as diagnostic or to interpret positive and negative results in the wrong direction. For example, seven women stated that a negative result meant that the baby was

Table 1 Section 1: all women

	Total	Yes	%	No	%	Don't know	%	No answer	%
Previous knowledge about the triple test	352	125	35.5	217	61.6	10	2.8		
Happy with how the test was first discussed	344	275	79.9	31	9.0	22	6.4	16	4.7
Did practice supply written information about the test?	344	217	63.1	72	20.9	37	10.8	18	5.2
Was the written information provided useful?	217	185	85.3	11	5.1	15	6.9	6	2.7
Understood what it meant to have a positive test result	344	282	82.0	15	4.4	16	4.7	31	9.0
Understood what it meant to have a negative test result	344	273	79.4	12	3.5	15	4.4	44	12.8
Did practice offer the triple test?	352	329	93.5	8	2.3	7	2.0	8	2.3

definitely healthy, while three stated that a positive result indicated a high chance of the baby being *healthy*.

Section 2 (Table 2)

A total of 83 respondents had declined the triple test. The majority ($n = 53$) declined because of an intention to continue the pregnancy, including an unwillingness to place it under any unnecessary threat. A smaller group ($n = 11$) considered that their personal circumstances reduced the need for testing (for example, a relatively young age).

Section 3 (Table 3)

In total, 208 respondents had a negative result. The main reasons for taking the test were to provide peace of mind ($n = 54$), to aid informed decision making ($n = 25$), to obtain information about the risk of abnormality ($n = 40$) and because of relatively advanced age ($n = 24$). Interestingly, a substantial proportion ($n = 21$) of women stated that the test had been taken because of the context in which it had been presented (i.e., as routine). The majority of women stated that they were happy with their decision to have the test. Of the women who were unhappy about their decision, two main reasons emerged, namely the fact that the results had been borderline, thereby failing to allay concerns ($n = 4$), and the fact that the women had taken the test under duress, and consequently were left feeling disempowered ($n = 2$).

Section 4 (Table 4)

A total of 41 respondents had a positive result (all false-positives). The main reasons for taking the test were relatively advanced age ($n = 12$) and to provide information about fetal health ($n = 11$). Four women stated that the test had been taken because of the context in which it had been presented (i.e., as routine). The majority of women stated that they were happy with their decision to have the triple test; the main reason for this

Table 2 Section 2: women who declined the test

	Total	Yes	%	No	%	Don't know	%	No answer	%
Happy with the decision to decline the triple test	83	79	95.2	1	1.2	3	3.6		
Did the practice staff provide the necessary advice to reach decision to decline?	83	57	68.7	12	14.4	13	15.6	1	1.3

https://doi.org/10.1191/146342300673020937 Published online by Cambridge University Press

Table 3 Section 3: women who had a negative result

	Total	Yes	%	No	%	Don't know	%	No answer	%
Happy with the decision to have the test	208	185	88.9	9	4.3	13	6.3	1	5
Practice provided sufficient information and advice about the test	208	170	81.7	19	9.1	13	6.3	6	2.9
Information was provided on how the triple test result would be received	208	157	75.5	27	13.0	23	11.1	1	5
Satisfied with how the triple test result was received	208	149	71.6	37	17.8	20	9.6	2	1.0
Satisfied with explanation of the triple test result	208	162	77.9	18	8.7	21	10.1	7	3.4

Table 4 Section 4: women who had a positive result

	Total	Yes	%	No	%	Don't know	%	No answer	%
Happy with the decision to have the test	41	25	61.0	10	24.4	6	14.6		
Practice provided sufficient information and advice about the test	41	25	61.0	6	14.6	10	24.4		
Information was provided on how the triple test result would be received	41	25	61.0	9	22.0	7	17.1		
Satisfied with how the triple test result was received	41	25	61.0	11	26.8	3	7.3	2	4.9
Satisfied with explanation of the triple test result	41	25	61.0	10	24.4	5	12.2	1	2.4
Satisfied with explanation of what will happen next because of the positive result	41	25	61.0	6	14.6	3	7.3	7	15.0

focused on the test's ability to provide information and thereby to help them to prepare for any eventuality ($n = 8$). Of the women who were unhappy about their decision, several stated that this was because the result led to further, unnecessary testing and concomitant anxiety ($n = 7$).

Section 5 (Table 5)

Five of the 41 women who had a positive triple test result declined to have a follow-up amniocentesis because of the risk of miscarriage. Another woman had a miscarriage while waiting for the amniocentesis. Several women chose not to have the triple test, opting for an amniocentesis on the grounds that it provided a diagnosis. One woman had a borderline negative triple test and chose to have an amniocentesis. As a result of these varying considerations, a total of 41 women had an amniocentesis during the period covered by the research.

The majority of these women ($n = 31$) stated that they saw this as the logical next step given their positive result and the higher risk of carrying an affected fetus that this implied. While this group of women appear to have reached a personal decision, a much smaller group ($n = 3$) had the

https://doi.org/10.1191/146342300673020937 Published online by Cambridge University Press

Table 5 Section 5: women who made a decision about amniocentesis

	Total	Yes	%	No	%	Don't know	%	No answer	%
Did the patient have an amniocentesis?	50	41	82.0	9	18.0				
Was she happy with the decision regarding amniocentesis?	41	32	78.0	4	9.8	2	4.9	3	7.3
Was information and advice about reaching the amniocentesis decision supplied?	50	27	54.0	9	18.0	3	6.0	11	22.0
Did the hospital explain how the amniocentesis results would be received?	41	33	80.5	1	2.4			7	17.1
Was the patient satisfied with how the results were received?	41	14	34.1	18	43.9	2	4.9	7	17.1
Was the patient satisfied with the hospital explanation of the amniocentesis result?	41	25	61.0	6	14.6	3	7.3	7	17.1

amniocentesis on being advised to do so. The majority of women were happy with their decision. A number of interrelated reasons were given for this, including that the negative result provided 'peace of mind' ($n = 10$), because of a need to 'know for sure' ($n = 6$), and to be 'fully aware' prior to the birth ($n = 4$). Interestingly, five women stated that although they were happy with their decision, misgivings remained, particularly, over the risk of miscarriage associated with the procedure. The four women who were unhappy about their decision concentrated on the fact that both the procedure itself and the wait for results caused considerable distress and anxiety. Most women considered that practice staff had supplied appropriate information to support their decision regarding the amniocentesis. Here, emphasis was placed on the fact that the information and advice provided allowed informed decision making ($n = 10$). Those women who were dissatisfied with the information and advice provided concentrated on the lack of appropriate support both before the amniocentesis, and particularly during the period of waiting for the results ($n = 6$).

Section 6 (Table 6)

Most respondents thought that all women should be offered the triple test. Two main reasons were given for this – first, that all women have a fundamental right of choice ($n = 107$) and secondly that the tests enable informed decision making ($n = 56$). A much smaller group ($n = 12$) concentrated on the fact that although the triple test allows an element of choice, careful consideration and explanation of the possible implications are needed. Of the women who stated that the test should not be available to all women, two main considerations emerged, namely that it should only be offered to women deemed to be 'high risk' ($n = 5$), and that the test should not be offered *at all* on the grounds that it causes unnecessary anxiety ($n = 5$). The undecided women raised a number of concerns, with some stating that the test should only be offered to women already deemed to be at high risk ($n = 4$).

Discussion

We attempted to uncover the reasons behind the response rate of 60.7% by examining the records of those women who did not respond. On doing so, we discovered that a significant proportion had experienced their pregnancies at the beginning of the 5-year period. Although we did not speak to any of these women, it is possible that a limited memory of relevant events meant that they did not consider themselves competent to complete the questionnaire. Mindful of this limitation, and given the fact that for each of the 'categories' of

https://doi.org/10.1191/146342300673020937 Published online by Cambridge University Press

Table 6 All women

	Total	Yes	%	No	%	Don't know	%	No answer	%
Should all women be offered the triple test?	352	271	77	20	5.7	33	9.4	2.8	8

responder (e.g., declined, negative result, positive result) the response rate was similar, we felt able to generalize the results to the total practice population.

The research was based in one general practice and used measures devised specifically for the purpose. Consequently, the findings are not intended to be comparative or generalizable. Rather, they suggest areas and issues that are likely to emerge as important in the context of primary care-based antenatal screening and, as such, are particularly important in that they are the first to be produced at a time when the momentum towards a primary care-led NHS is increasing. All previous studies on the psychosocial effects of screening have taken place in a hospital clinic setting.

Previous research has emphasized that, in order to qualify as an effective antenatal screening tool, any programme should fulfil certain requirements (Cuckle and Wald, 1984). In relation to women's understanding of these requirements, this study has highlighted a number of key issues. These are discussed below in the context of a consideration of the implications raised for the delivery of appropriate antenatal (screening) care. We confine our discussion to primary care.

Overall, the women who were surveyed stressed the fundamental importance of personal, one-to-one communication regarding all aspects of the triple test and associated procedure(s). However, they also welcomed the written (leaflet) information provided by the practice during initial discussion of the test, on the grounds that it afforded the opportunity for extended, independent consideration. Other studies have shown that such leaflets improve knowledge as well as increasing satisfaction with the subsequent experience of taking the test (Marteau *et al*., 1993). Our findings confirm the value of written information, with the important proviso that such information remains totally impartial.

The issue of perceived (im)partiality in advice and information-giving emerged as particularly important in two related ways. First, it was found that some women took the test because it was presented as routine. Hospital doctors and midwives have been reported to emphasize the practical aspects of the test rather than its implications (Smith *et al*., 1994) and this may have been the case here. The rate of practice uptake of the test was relatively high, at around 77%. Where uptake levels have been similarly high, concerns have been raised that some women are agreeing to the test in the absence of full knowledge and understanding (Dawson *et al*., 1993; Saridogan *et al*., 1996). Secondly, complaints were made by some women about what they perceived to be pressure exerted by practice staff to take the test, a situation which has also been reported in other settings (Marteau *et al*., 1992b). In a number of cases this perception of pressure being applied encouraged dissatisfaction throughout the testing procedure, regardless of the eventual outcome. Concomitantly, when women considered that their decision (not) to have the test had been respected, their overall satisfaction with all aspects of care provided was high.

The procedure adopted by the practice for communicating test results involved direct communication of screen-positive results only. This study has demonstrated the inappropriateness of such a system. Although the majority of women were given information regarding feedback of results, and indeed accepted the arrangement, the subsequent waiting period provoked considerable anxiety and distress, with the result that many women were compelled to seek out the result in order to bring that wait to an end and/or obtain the necessary reassurance.

The study also highlighted the dangers inherent in assumptions made by health professionals concerning women's information requirements. For

https://doi.org/10.1191/146342300673020937 Published online by Cambridge University Press

example, with regard to screen-negative results, some women were dissatisfied with being informed, often by a nonmedical member of staff, that their test result was 'simply' negative. They required a much fuller explanation of the meaning of 'negative', and clearly this could only be provided by a relevant member of the practice staff.

The need for detailed, explicit information is all the more urgent given the susceptibility of some women to interpreting a screen-negative result as proof that their pregnancy is unaffected, as demonstrated by this and previous studies (Roelofson *et al*., 1993). In this regard it is particularly important not only to address immediate information requirements, but also to make women fully aware of all possible outcomes, including the decisions which may have to be made.

Abnormal screening results have been shown to be associated with the development of significant anxiety (Abuelo *et al*., 1991), which may be reduced by counselling (Keenan *et al*., 1991). In line with previous work (Santalahti *et al*., 1996), our study has highlighted how, after having taken the triple test, many women subsequently come to associate it with unnecessary anxiety. While anxiety may be resolved later, once diagnostic testing has ruled out abnormalities (Marteau *et al*., 1992a), some women remain anxious throughout the remainder of their pregnancy (Statham and Green, 1993). The opportunity to discuss their ongoing concerns would have been welcomed by these women.

With regard to a screen-positive result, previous work has emphasized the need for the procedure after such a result to be generally agreed upon by and acceptable to both patients and professionals (Cuckle and Wald, 1984). This study has demonstrated that a key factor in achieving such acceptability is the provision of counselling both during and, importantly, after the decision-making process. All women found the period of waiting for the amniocentesis result very stressful, and described how the opportunity to discuss their concerns would have gone some way towards helping them through the wait. Indeed, the issue of continuity of care emerged as fundamentally important in helping women to cope with the inevitable distress and anxiety experienced as a result of a positive screening result. Although they were referred to secondary care at this stage, it was to primary care practitioners that women looked for support.

Despite this, the findings suggest that those women who experienced a screen-positive result were less likely to be satisfied with the care that they received from practice staff. At one level this contradicts the notion (including that held by the majority of our responders) that primary care is best placed to meet the needs of such women. However, there is nothing in our research findings to suggest that primary care is not capable of meeting these needs provided that certain arrangements are in place. In this regard, when asked how the practice might improve the care provided, responders made two main suggestions. First, they suggested that the procedure for relaying screen-positive results required improvement, and in particular that positive results should be communicated in person with the opportunity for extended discussion. Secondly, they suggested that once a woman has been given a screen-positive result, she should have access to a relevant individual or individuals capable of providing both emotional support and practical advice.

On the wider issue of availability of screening tests, it has been suggested that all women who may benefit from a screening test should have access to it (Wald *et al*., 1997a). Our findings suggest that 'benefit' cannot be assessed exclusively in clinical terms, in that the women surveyed considered the triple test to have the potential to improve the experience of pregnancy for all women, not just those deemed to be 'high risk'. This remained the case whether or not the women identified problems with screening (primarily the lack of diagnostic capability).

Overall, the study confirms the view that antenatal screening is not simply a matter of performing the appropriate test(s) and reporting the results (Wald *et al*., 1997b). Much more is involved, particularly in relation to the provision of support and counselling at all stages of the testing procedure. With regard to primary care in particular, the requirement to provide ongoing support, including cases for which a referral to secondary care has been made, is clear. It is understandable that, when seeking ongoing support, women turn first to the members of their local primary care team. Clearly, the provision of *community-based* antenatal screening should not cease simply because the woman is referred out of that community setting.

In total, 5 years of testing cost £21 669. There

were no Down's syndrome births prevented, but neither were any missed. Discussing the test takes extra time within at least one consultation and one antenatal appointment. Screen-positive results and their aftermath are stressful for both patients and doctors. With the coming demise of fundholding and the birth of locality commissioning groups, there is doubt that offering the triple test will be viewed as cost-effective. The test may once again revert to being offered only to women of a certain age, an outcome that would conflict with the view of the majority of our respondents.

Acknowledgements

This study was financed by a grant from the Royal College of General Practitioners. We would also like to thank the women registered with the Hebden Bridge Group Practice and the doctors and community midwives who work there, Brett Scaife for help with the analysis and Liz Cockayne for administrative support.

References

Abuelo, D.N., Hopmann, M.R., Barsel-Bowers, H.G. and **Goldstein, A.** 1991: Anxiety of women with low maternal serum alpha-fetoprotein screening results. *Prenatal Diagnosis* 11, 381–85.

Cuckle, H., Ellis, A.R. and **Seth, J.** 1995: Provision of screening for Down's syndrome. *British Medical Journal* 311, 512.

Cuckle, H.S. and **Wald, N.J.** 1984: Principles of screening. 1984: In: Wald, N.J., editor, Antenatal and neonatal screening. Oxford: Oxford University Press, 1–22.

Dawson, A.J., Jones, G., Matharu, M.S., Reynolds, T.M., Penney, M.D., John, R. *et al.* 1993: Serum screening for Down's syndrome. *British Journal of Obstetrics and Gynaecology* 100, 875–77.

Department of Health 1993: *Changing childbirth. Report of the Expert Maternity Group.* London: HMSO.

Hewison, J. 1996: Prenatal screening. In Niven, K.A. and Walker, A., editors, *Conception, pregnancy and birth.* Oxford: Butterworth-Heinemann, 74–86.

Keenan, B.L., Basso, D., Goldkrand, J. and **Butler, W.J.** 1991: Low levels of maternal serum alpha-fetoprotein: its associated anxiety and the effects of genetic counselling. *American Journal of Obstetrics and Gynaecology* 164, 54–56.

Marteau, T.M., Cook, R., Kidd, J., Michie, S., Johnston, M., Slack, J. *et al*. 1992a: The psychological effects of false-positive results in prenatal screening for fetal abnormality: a prospective study. *Prenatal Diagnosis* 12, 205–14.

Marteau, T.M., Slack, J., Kidd, J. and **Shaw, R.J.** 1992b: Presenting a routine screening test in antenatal care: practice observed. *Public Health* 106, 131–41.

Marteau, T.M., Cook, R., Kidd, J., Michie, S., Cook, R., Johnston, M. and **Slack, R.W.** 1993: Anxiety, knowledge and satisfaction in women receiving false-positive results on routine prenatal screening: a randomised control trial. *Psychosomatic Obstetrics and Gynaecology* 14, 186–96.

Mutton, D., Ide, R.G. and **Alberman, E.** 1998: Trends in prenatal screening for and diagnosis of Down's syndrome: England and Wales. *British Medical Journal* 317, 922–23.

Roelofson, E.E.C., Kamberbeck, L.I., Tymstra, T.J., Beekhuis, J.R. and **Mantingh, A.** 1993: Women's opinions on the offer and use of maternal serum screening. *Prenatal Diagnosis* 13, 741–47.

Santalahti, P., Latikka, A.M., Ryynanen, M. and **Hemminki, E.** 1996: Women's experiences of prenatal serum screening. *Birth* 23, 101–7.

Saridogan, E., Djahanbakhch, O. and **Naftalin, A.A.** 1996: Screening for Down's syndrome: experience in an inner city health district. *British Journal of Obstetrics and Gynaecology* 103, 1205–11.

Smith, D.K., Shaw, R.W. and **Marteau, T.M.** 1994: Informed consent to undergo serum screening for Down's syndrome: the gap between policy and practice. *British Medical Journal* 309, 776.

Smith L. 1996: Should general practitioners have any role in maternity care in the future? *British Journal of General Practice* 46, 243–47.

Statham, H. and **Green, J.** 1993: Serum screening for Down's syndrome: some women's experiences. *British Medical Journal* 307, 174–76.

Wald, N.J., Cuckle, H.S., Densem, J.W. *et al*. 1988: Maternal serum screening for Down's syndrome in early pregnancy. *British Medical Journal* 297, 883–87.

Wald, N.J., Huttly, W., Wald, K. and **Kennard, A.** 1996: Down's syndrome screening in the UK. *Lancet* 347, 330.

Wald, N.J., Kennard, A., Hackshaw, A. and **McGuire, A.** 1997a: Principles of screening for Down's syndrome. *Journal of Medical Screening* 4, 185–87.

Wald, N.J., Kennard, A., Hackshaw, A. and **McGuire, A.** 1997b: Psychosocial aspects. *Journal of Medical Screening* 4, 233–37.