

J. Burn^a
 S. Fairgrieve^{a,b}
 P. Franks^b
 I. White^a
 D. Magnay^a

^a Northern Region Genetics Service and

^b Department of Obstetrics and Gynaecology,
 Ashington Hospital, Ashington,
 Northumberland, UK

Audit of Maternal Serum Screening: Strategies to Augment Counselling in Response to Women's Views

Abstract

Women's opinion on the maternal serum screening programme offered at one maternity unit in East Northumberland (1991–1992) was evaluated. The responses from 1,774/2,633 women showed a general acceptance of the test but 722/1,774 (40%) wanted more information and a third, more explanation. Recommendations, which included a 'gold standard' protocol, a video to complement revised patient information literature and a coordinator to facilitate interdisciplinary communication and training with support for midwives, were introduced. The audit cycle was completed by a repeat questionnaire survey of 2,489 women from the postnatal ward (1992–1994) with a 67.3% response. An overall improvement in levels of satisfaction with reduction in, but not eradication of, the need for more information and explanation had occurred. These findings have relevance to the current controversy surrounding the counselling implications of maternal serum screening and have led to the formation of a network of professionals to develop the programme in our region.

Key Words

Down's syndrome
 Audit cycle
 Women's views
 Video
 Genetic counselling

Introduction

Although a variety of studies [1–8] have shown that maternal serum screening can improve the antenatal detection of Down's syndrome, rather than the use of maternal age alone, the widespread concern expressed about the moral justification and economic implications of this approach has led to lack of consensus and a patchy development of services in the UK as well as other countries. Nonetheless, recent estimates suggest that about 60% of women in Britain and just under a half in the USA have access to serum screening in pregnancy [9]. The fact that early studies [10, 11] from centres where such testing was offered as routine, reported problems attributable to women's lack of understanding of the test, was not so surprising, given the complexity of the information and pro-

professionals' unfamiliarity with its communication. The consequent counselling requirements were then outlined but despite these recommendations, difficulties still remain, as reported in a recent survey of obstetricians [12] and a review of current practice [13]. The situation described is more one of despair, with a call for 'effective staff training' and 'clear unbiased knowledgeable advice' for the women but without practical suggestions. The Northern Region Genetic Service has provided maternal serum screening since 1980, originally to detect neural tube defects. The service was extended to include screening for Down's syndrome in 1989. Our laboratory data on efficacy agreed with published studies [1–8] and was accompanied by regular clinical reviews but prior to this study there had been no opportunity for a formal evaluation of women's opinions. Anecdotal comments suggested

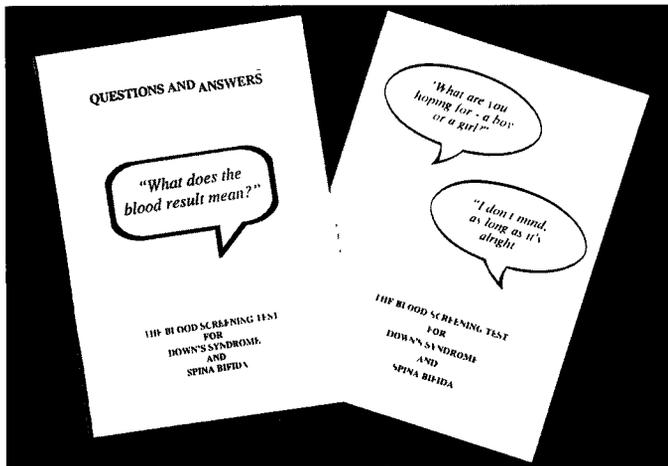


Fig. 1. Patient information leaflets: general and 'at increased risk' result.

that there might be an unacceptable level of adverse psychological sequelae. We present the findings of an initial audit, together with a description of changes undertaken as a consequence and the second audit, thus completing the audit cycle [14]. To our knowledge, this represents a hitherto unique insight into participants' view of maternal serum screening.

Materials and Method

Almost all pregnant women in East Northumberland book for obstetric care through one of four consultants based at Ashington Hospital. This maternity unit has approximately 2,200 deliveries per year and was the first in the region to offer maternal serum screening to all women. During the period of our study, the average uptake was 75%. Although the original 1980 protocol for the introduction of the screening programme, patient information leaflets and letters were still available, modifications had been required so that there was no longer a routine practice within the unit. Serum samples were sent to the Northern Region Genetics Service laboratory and analysed using AFP, total hCG, maternal age and gestation to provide a risk estimate for neural tube defect and Down's syndrome [15]. Approximately 5% of women screened were offered further investigations. All general practitioners were notified and gave permission for their patients to be approached. The study was granted ethical approval.

Preliminary Audit

A self-completing questionnaire was issued to:

- a consecutive series of women from whom a serum sample had been obtained during a 1-year period from 1.7.90 to 30.6.91 (1,796 subjects);
- a consecutive series of women from whom a serum sample had been obtained and an 'at increased risk' result for Down's syndrome or neural tube defect had been given during the additional periods 1.3.89 to 30.6.90 (71 subjects) and 1.7.91 to 31.12.91 (17 subjects);

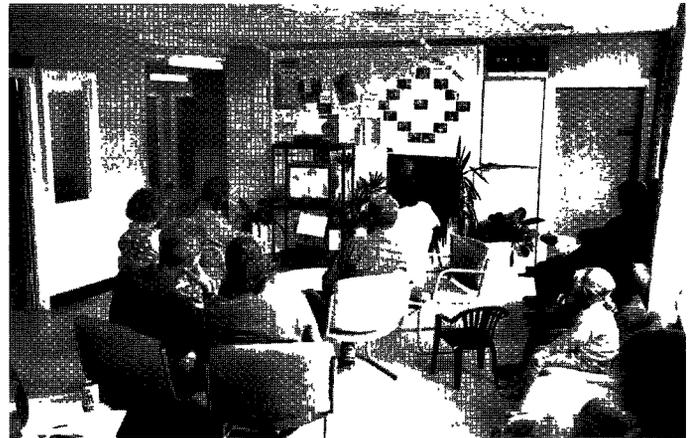


Fig. 2. Viewing of video during antenatal clinic.

- a consecutive series of women who had recently delivered on postnatal wards at Ashington maternity unit over a 4-month period 16.3.92 to 16.7.92 (745 subjects).

A semistructured questionnaire was completed by the research midwife at interview in the women's own home or on the postnatal ward with women who had completed the self-completing questionnaire and had been designated 'at increased risk' for Down's syndrome or neural tube defect (194 subjects).

During the total study period, 150 women were 'at increased risk' for Down's syndrome and 203 for neural tube defect. Of these, 194 returned the questionnaire and 114 were interviewed, 79 'at increased risk' for Down's syndrome and 35 for neural tube defect.

Implementation of Changes

Based upon analysis of the preliminary audit questionnaires, the following measures were undertaken. The bland patient information leaflet was redesigned to be more 'user-friendly', using a question and answer format. Much consideration was given to readability levels and the language used, such as 'at increased risk/not at increased risk' rather than 'positive/negative' (which tends to sound more definite). Additional leaflets were produced to help deal with questions raised by receipt of an 'at increased risk' result (fig. 1). Letters to patients communicating their results were redesigned and arrangements made for those which were 'at increased risk' to be notified by a home visit from a midwife. A 15-min video was scripted and presented by JB explaining the nature of Down's syndrome and neural tube defect, the blood test and amniocentesis. In this we had tried to project the need to balance the risks and benefits of screening, as later suggested by Allaby [16], using the image of a see-saw. We intentionally used some of the same phrases and statements as in the patient literature so that they were complementary, in the hope that this would have the double benefit of encouraging all professionals to 'speak the same language' as well as present a less confusing message to women. After a satisfactory 'pilot' assessment by pregnant women and professionals, this was shown in the hospital antenatal clinic (fig. 2). Community midwives were provided with copies to show at GP's surgeries or for women to view in their own homes. A more formal system of training

Table 1. Comparison of self-completing questionnaires.

	Preliminary audit	Follow-up audit	Comparison to first cohort
Total cohort	1,774 (100)	1,676 (100)	
Heard about test from midwife	1,043 (58.8)	1,085 (64.7)	p = 0.00019
Test explained by midwife	1,374 (77.4)	1,295 (77.3)	p = N.S.
Received leaflet	1,337 (75.4)	1,364 (81.4)	p < 0.00001
Wanted more explanation	591 (33.3)	379 (22.6)	p < 0.0001
Wanted more information	772 (40.7)	482 (28.8)	p < 0.0001
Would have test in future pregnancy	1,631 (91.9)	1,420 (84.7)	p < 0.0001
Test should be available to all	1,735 (97.8)	1,628 (97.1)	p = N.S.
'At increased risk' cohort	194 (100)	116 (100)	
Would have test in future pregnancy	154 (79.4)	107 (92.2)	p = 0.0016
Test should be available to all	183 (94.3)	114 (98.3)	p = N.S.

Figures are numbers and percentages (in parentheses) of women's responses.

and updates for community staff in East Northumberland was also introduced. This included a training video explaining basic genetic information as well as maternal serum screening. A midwifery coordinator was nominated to streamline the day-to-day operation of the programme and to provide professional support for midwives.

Second Audit

A self-completing questionnaire with additional questions for those reporting to have seen the video, was used to a consecutive series of women who had recently delivered on postnatal wards at Ashington maternity unit over a 14-month period from 15.12.92 to 15.2.94 (2,489 subjects).

Statistical Analysis

χ^2 analysis, t test and Fisher's exact test were used in the analysis of the data. A probability of less than 0.05 was accepted as significant.

Results

Preliminary Audit

Self-Completing Questionnaire. Of 1,884 postal questionnaires and 745 postnatal ward questionnaires, 1,171 (62%) and 603 (81%) were returned respectively. Of the total analysed, 194 (10.9%) had received an 'at increased risk' result. Table 1 summarises the most relevant findings. Not all women reported that they had received a patient information leaflet. Although 1,292 of 1,337 who had received a leaflet found it helpful, 342 (25%) wanted more explanation and 442 (33.1%) more information. Of those respondents who denied having received the leaflet, 245 (57%) wanted more explanation and 276 (64.8%)

more information. Serum samples were obtained at either the main antenatal clinic, one of four satellite clinics or at the GP surgery and 96% expressed satisfaction with these arrangements. Of the total of 1,644 who were screened, 1,449 (88.1%) were satisfied with the means of communication of result. This was by letter for 1,315 (79.9%), 245 (14.9%) heard from the midwife, 73 (4.4%) heard from the GP, 36 (2.2%) by telephone and 35 (2.1%) from the hospital doctor. Dissatisfaction was expressed with the mode of communication by 167 (10.2%). The greatest proportion of complaints were among the telephone group, 11/36 (30.6%). For 1,474/1,644 (89%) their experience of maternal serum screening had been satisfactory.

Interviews with 'at Increased Risk' Women. Of the 114 women approached for interview, all agreed to participate. Responses revealed that 65/114 (57%) described themselves as 'devastated' and 21% as 'worried' when they received their result of the serum test; 49 women (43%) obtained adequate explanation at the time of receiving the result but 65 (57%) did not. The level of anxiety was probably reflected in the 24% who felt that waiting more than 2 days for an appointment was too long. Counselling given prior to and specific for further investigations was considered helpful by 95/114 (83.3%). In the small number of those who expressed dissatisfaction, there was no clear difference between designation of staff (i.e. obstetrician, geneticist or midwife) or the length of time taken for counselling. Amniocentesis had been performed on 74/114 women; 35% forgot about the test when given a normal amniocentesis result but 51% were 'occasionally worried' and 12% were 'constantly worried'. The

majority (71%) were pleased that they had had maternal serum screening, 13.2% were sorry and the remainder were undecided.

Second Audit

Table 1 summarises the comparative results of 1,676 completed questionnaires. These represent 67.3% of all deliveries: 1,350 (80.5%) reported that they had had serum testing comparable with 81.3% uptake in the population for the second audit time period. Of these, 1,292 (95.7%) were satisfied with the test and 1,256 (93%) were satisfied with the method of communication of their result. The majority 302/343 (86%) of women who reported they had seen the video watched it at Ashington maternity unit. Some 249 (72.6%) watched it from start to finish and 270 thought the length was about right. Opinions about the content of the video are summarised in table 2 and as regards Down's syndrome, were representative of opinions concerning other information given. Two hundred and eighty-six had seen both the leaflet and the video and of these, only 52/286 (18.2%) felt in need of further explanation and 68/286 (23.8%) would have liked more information, significantly less ($p = 0.0276$ and 0.0231 , respectively) than in the total population (1,676). A clear majority (66.2%) indicated that the video was more helpful than the leaflet and a similar proportion 204/343 (59.9%) thought that the video was easier to understand.

Discussion

The 'audit cycle' and introduction of a 'gold standard' protocol proved to be a good framework to remedy identified deficiencies. Rather than examine women's knowledge as an indicator of the adequacy of counselling, we felt that women's perceptions were a more realistic estimate. The clear-cut findings of this study lend support to this method of enquiry. We revealed, somewhat unexpected, high levels of acceptance in those who decided against the test for themselves. Even when women had had the worrying experience of an 'at increased risk' result, most would have the test again. In some women, expressed need for further information and explanation may reflect latent anxiety but provision of a combination of audiovisual and printed material to supplement, but not replace, counselling did appear to help minimise this difficulty. Although those who reported seeing the video were relatively few in number, this could be attributed to the 'low key' arrangements for viewing and diversity of other antenatal clinic

Table 2. Women's opinions of the video: total 343

	Number
<i>Thought that video was</i>	
Interesting	107 (31.2)
Helpful	171 (49.9)
Informative	122 (38.6)
Worrying	36 (10.5)
Confusing	4 (1.2)
Boring	5 (1.5)
<i>Information about Down's syndrome</i>	
Very clear	89 (25.4)
Easy to understand	235 (68.5)
Hard to understand	11 (3.2)
Very confusing	2 (0.6)

Figures in parentheses are percentages.

activities. We believe that the favourable response obtained justifies continued interest in the development of this novel intervention, both as an added source of professional training as well as for use by the women.

Our audit highlighted the major role of midwives, a feature also observed by Khalid [17]. Their function had undergone a transition from a supportive role to being the main source of information about all aspects of screening and heavily involved in delivering unwelcome news. Not surprisingly, midwives did not find this an easy task and some came to dread the prospect. With a 'coordinator' for midwives (SF) nominated, who could offer both patient and professional support, this problem was alleviated to some extent. A variety of different professionals may undertake counselling, however organised professional support should still be made available. We recommend a formal induction for all new employees as staff turnover was an additional reason for failure to adhere to the protocol. With the passage of time, familiarisation will occur. However, the need for updating and training of professionals is continuous and should not be underestimated.

We have used the experience gained from this study to assist with the development of screening in the rest of the Northern region. Practical details and recommendations are contained in a pack given to a key person (coordinator) for each maternity unit. Their role includes responsibility for the reliable relay of information between laboratory, professionals and women as well as completion of a basic data set for audit purposes. Half-yearly meeting with

all coordinators at the Northern Region Genetic Service for update and review facilitates the cascade of information to participating units.

'Outreach' professionals appear to appreciate these arrangements which help to maintain standards and avoid complacency. Following the completion of this study and informal dissemination of our findings at regional meetings and national conferences, we have received requests for our protocol, manual for health professionals, videos and patient information literature. We understand that several areas have adopted some or all of these for their own purpose. Within the UK, there is, as yet, no national protocol.

Conclusion

Evaluation is an essential component of population screening and an audit of consumer satisfaction can make a useful contribution. There is almost universal support in our population for the availability of maternal serum screening amongst pregnant women and most will request testing.

Women require clear, accurate and consistent information in order to decide whether to undergo maternal serum screening. This may be achieved by identification of a key professional within each unit who will be responsible, not only for the relay of results to women but also for communication between professionals. Their role should include responsibility for arranging the necessary training and regular updating of all involved professionals.

The major European challenge will be to translate these observations into practice across different cultural groups and in more dispersed health care systems.

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