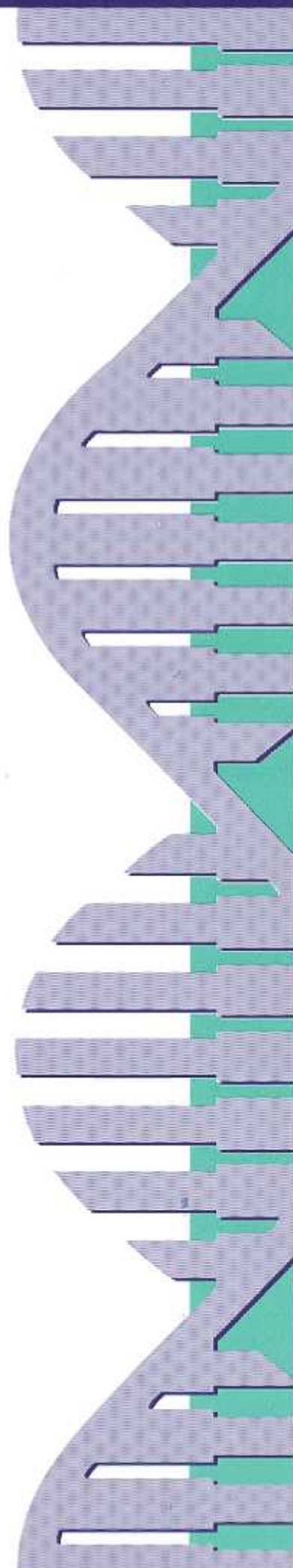


Prenatal Screening and Diagnosis

A survey of health care providers'
experiences



Department of Health
Government of Western Australia



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October 2002

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Western Australia

Acknowledgments

The authors wish to acknowledge the contributions of:

The Royal Australian and New Zealand College of Obstetricians and Gynaecologists for their support.

King Edward Memorial Hospital, Clinipath, Western Diagnostics Inc. and St John of God Pathology for assistance with the collection of data;

All members of the Reference Group for their professional advice.

All the health professionals who took the time to take part in the survey.

Citation

Rostant, K., Steed, L. & O'Leary, P. (2002). *Prenatal screening and diagnosis: A survey of health care providers' experiences*. Genomics Occasional Paper 3. Department of Health, Perth, Western Australia

Abstract

Objective: To ascertain the level of services provided by health care providers in Western Australia and to identify their informational needs with regard to prenatal screening and diagnostic procedures.

Design: A self-administered mail survey.

Sample: 30 obstetricians and 313 general practitioners. The average age of participants was 43.5 years, 49% were male, 49% were female, and 69% were situated in the metropolitan area and 24% in the rural area. A small percentage did not select their gender and/or area of practice.

Results: Most (90%) health care providers in Western Australia performed less than 6 first or second trimester screening tests in 2001. Furthermore, 41% of health care providers felt there were characteristics of the patient that effect how prenatal screening tests should be offered, 63% preferred to offer first, as opposed to second, trimester screening and 57% felt there were barriers to providing first trimester screening. Obstacles to providing patients with information included constraints in office time, rapidity of advances in genetic testing and a lack of patient-oriented-literature. Health care providers preferred sources of information for themselves were published references, the laboratory, ultrasound units and their colleagues. Health care providers reported that it took significantly longer to receive results advising a second trimester at increased risk and not at increased risk compared to first trimester results.

Conclusion: A lack of experience in providing prenatal testing and the possible sharing of inconsistent information is concerning. It is evident that the provision of professional development by health professional educators remains an area of urgency. It is proposed that those preferred sources of information identified by health care providers be investigated as possible avenues for professional development and education.

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Introduction

Information on prenatal procedures has been identified as an important first step for women in the decision to undergo prenatal screening and diagnosis. Women often rely on the information received from their health care provider; thus it is important that this information is thorough and reliable. However, earlier research has identified gaps in health care providers' knowledge of these procedures, particularly with regard to the presentation and meaning of results and the sensitivity of screening tests.¹⁻⁴

It is clear that reduced knowledge of screening and diagnosis in the health care provider will result in incomplete information being imparted to women. Less evident, however, is that for those care providers who have adequate knowledge there is no guarantee that this knowledge is being communicated. Smith et al.⁵ highlight that other factors are important in predicting what information is communicated. For example, beliefs about the importance of information to decision-making and attitudes towards providing information influence pre-test counselling information. As a result, research into service provision is vitally important to determine the extent to which pre- and post-test counselling are being provided. Regrettably, earlier studies have reported deficits in service provision and pre-test counselling of prenatal screening and diagnosis.

First, health care providers may selectively offer antenatal screening tests. Carroll et al.¹ surveyed health care providers in Canada who did not offer second trimester screening to all pregnant women. They were more likely to offer screening to women aged over 35 at delivery, those with a family history of Down syndrome, or neural tube defect, and to those who requested testing. In addition, Yankowitz, Howser and Ely⁶ found that American family physicians, as opposed to obstetricians, were less likely to offer maternal serum screening (MSS) procedures to all pregnant women. Alternatively, family physicians would offer screening to those women whom they felt would benefit, that is, women who would consider a termination of a fetus identified as at increased risk of having a genetic condition. Similarly, Hunter et al.⁷ reported that

30% of obstetricians, gynaecologists and physicians would only refer a woman if a termination were accepted as an option.

Furthermore, the health care provider can influence women's decisions regarding prenatal procedures through the way the tests are introduced or presented. Gekas et al.⁸ found that for 42.5% of women in their study, maternal serum screening (MSS) was recommended by the provider, 41.5% stated that it was imposed and a further 16% claimed it was performed without their consent. In addition, Carroll et al.¹ surveyed Canadian health care providers (general practitioners, midwives and obstetricians) in relation to MSS and it was identified that 22% of them carried out the procedure without the consent of their patient. Although women may seek advice as to what tests should be undertaken, it is the duty of the health care provider to provide complete information and non-directive counselling.

Once a test has been presented as available, care providers can shape women's understanding of the meaning and purpose of screening through the information that is provided⁹. In the study conducted by Smith et al.⁵, it was found that in fact care providers will disclose information that they perceive to be important in the decision making process of pregnant women. Bramwell and Carter¹⁰ identified that midwives and obstetricians would give information on screening based on their own experiences and give advice based on the choices they themselves would make.

Ideally, the care provider's role is to provide the patient with comprehensive and unbiased information and present all the options available to enable her to make an informed decision. Following this, the health care provider should provide reassurance that s/he will support the patient in whatever option is chosen.¹¹ It has been argued, however, that non-directive service provision is not achievable in practice, as it is inevitable that the care provider will bring into it his/her own cultural background, value systems, personality and life experiences. As a result, these may influence, either consciously or unconsciously, the words used to describe choices, conditions or the tests available.¹² However, it is the responsibility of the health care provider, in accordance with best practice, to have a higher awareness of these influences so that their impact on service

provision may be reduced. This would enable the health professional to provide information to women, both written and verbal, in a non-judgemental way, allowing women to make a decision that is appropriate for them.

With regard to the presentation of results, further deficits in service provision have been documented. Carroll et al.¹ established that less than 25% of Canadian health care providers communicated negative results to women as soon as they were received, 62% communicated them at the next visit, 11% delegated the task to someone else and 4% stated they do not communicate negative results. These findings are not in line with women's expectations of service. As stipulated by the women in a later study conducted by Carroll et al.¹³, they wanted their general practitioner (GP) to communicate results, whether positive or negative, in an accurate and timely manner and were opposed to only being contacted if the results indicated an at increased risk result.

There is an obligation for the health care providers to communicate to women not at increased risk results. As one midwife stipulated, "They (GPs) are still at the low risk equals no risk stage, so a low risk result gets looked at and 'oh well that's OK' and then they just file it...Some of them (patients) still come back to clinic four weeks later and want to know if the blood test results are back" (p.19).¹⁴ Given the possibility of a 'false negative' result it is important that a comparable amount of time is dedicated to giving and explaining a not at increased risk result as is given to an at increased risk result.

Barriers to providing adequate counselling, information and services have been identified by health care providers. In a study conducted by Green¹⁵ in the United Kingdom, 46% and 30% of obstetricians were found to comment that they did not have sufficient resources to provide adequate counselling for screening and diagnosis respectively. In this same study, 33% of respondents indicated that outside pressures prevented them from implementing certain procedures that they considered beneficial. Ryder¹⁴ identified that some midwives felt the area of prenatal screening is changing too rapidly and they felt it was difficult to keep up with the most relevant research in the area. Similar results were found by Wilkins-Haug et al.⁴ who conducted a survey study to investigate practice trends of obstetricians in the United States. The greatest

obstacle identified to providing patients with information about genetic issues was the rapidity in advances in testing for genetic conditions. Other obstacles included constraints in office time to adequately address women's concerns and a lack of patient-oriented-literature. However, it was further identified that care providers were able to provide adequate resources regarding neural tube defects and Down syndrome.

In an analysis of information-seeking behaviour a range of resources has been nominated as preferences for sources of information on genetic and screening issues, including medical journals^{16,17} and continuing medical education courses¹⁸. Bowden et al.¹⁶ and Hofman et al.¹⁸ further documented that health care providers' frequently consult their peers. Considering the above findings pertaining to deficits in knowledge and service provision, it is of concern that peers are one of the preferred sources of information for health care providers. It is plausible therefore, that inaccurate information and practice methods will continue to be shared.

In the Australian context, Metcalfe et al.¹⁹ documented that GPs recognised the need to improve their counselling skills and believed that this should be emphasised in any educational program. Furthermore, content of these educational programs should be relevant to their day-to-day practice and should make a difference to their management of patients. For example, content should include taking family histories, drawing pedigrees, genetic testing, counselling skills and information about how and when to refer. GPs preferred education strategies to include reference folders and seminars and courses that are free, short and earn continuing medical education (CME) points. In another study, GPs in a selected area of Western Australia acknowledged that further genetic education was required and identified that practical information would be useful, for example, identifying patients who might benefit from genetic counselling.²⁰

The above findings suggest that greater provider education and support is needed. The Department of Health in Western Australia established an education program in response to the need for information on genetic conditions. One of its objectives is to raise awareness not only within the community, but also with health professionals, of genetic conditions and services available. The literature highlights, however, the important deficits in knowledge and service

provision of health professionals in the area of prenatal screening and diagnostic procedures. Thus, the present study aims to explore the level of services provided by health care providers in Western Australia and to identify their informational needs with regard to prenatal tests.

2 Method

2.1 Participants

All obstetricians and general practitioners (GPs) in Western Australia (WA) who regularly see pregnant women were eligible for participation. The Royal Australian and New Zealand College of Obstetricians and Gynaecologists provided a master list of all actively practicing obstetricians in WA ($n = 62$) of which three were invited to participate in a Reference Group. Of the remaining 59, 30 responded. Names and contact details were not available on the GPs seeing pregnant patients, thus surveys were sent to all 1925 GPs in WA. Of these 10 were returned as the wrong address. Responses were received from 463 (24%) GPs. Those who claimed they did not see pregnant patients on a regular basis ($n=140$) and those who reported they had retired ($n=10$) were excluded. The average age of participants was 43.5 years of age. Fifty percent (50%) were male, 50% were female. Sixty nine percent (69%) practiced in the metropolitan area, 24% practiced in the rural area and 7% did not specify their practice location. GPs graduated with their qualifications an average of 17 years previous, GPs with postgraduate qualifications 13.5 years previous and obstetricians an average of 18 years previous. Twenty six percent (26%) of all respondents had never attended an educational conference or workshop where prenatal screening or diagnosis was a significant part of the program.

2.2 Measures

The information of interest was collected via an 89-item self-administered mail survey (see Appendix II) that took approximately 15 minutes to complete. The final survey consisted of four sections targeting attitudes (23 items), knowledge (22 items), demographic information (14 items) and service provision (30 items). The section of service provision included items addressing the introduction of prenatal screening to patients, barriers to providing screening, the information given to patients, obstacles to providing information, the presentation of results and counselling. The response format included selecting from a range of responses, Likert scales and open-ended questions. Items were adapted from those constructed in earlier studies^{1,4,7,21} Furthermore, a

reference group consisting of health professionals was established so that content validity could be assessed. The survey was also pilot tested on 50 health care providers, 8 obstetricians and 42 GPs.

2.3 Procedure

Following approval by the Curtin University Human Ethics Committee, the survey was mailed out together with a covering letter (see Appendix III) and reply paid envelope. Return of the completed survey was deemed consent to participate. To allow for anonymity of responses, participants were not required to include their name or contact details, as a result a reminder letter (see Appendix IV) was sent to all health professionals. Data were also collected from the laboratories in Western Australia, King Edward Memorial Hospital, Clinipath, Western Diagnostics Inc. and St John of God Pathology, to determine the number of first and second trimester prenatal screening tests being ordered by health care providers in Western Australia.

3 Results

Of the 59 obstetricians, responses were received from 30 equating to a response rate of 51%. A final sample of 313 GPs who responded to the survey were eligible to participate. According to hospital and clinical data there are approximately 1625 GPs actively providing antenatal care in WA of which 75% are ordering less than six screening tests per year. This (1625) is the number of provider numbers against which a screening test has been ordered, however, it is possible that one GP has different provider numbers for each practice site, thus is likely to be an overestimate. Using this number of 1625, a final response rate of 19% was received from the GPs providing care, which is likely to be an underestimate.

The average number of pregnant patients seen in a year was 215, 31 and 58 for obstetricians, general practitioners and general practitioners with postgraduate qualifications, such as a Diploma in Obstetrics, respectively. Table 1 indicates the numbers and percentages of health care providers (GPs and obstetricians) providing first and second trimester screening tests for the year 2001.

Table 1

Numbers and percentages (in parentheses) of health care providers (by provider number) providing first and second trimester screening tests

| | | Number of Second Trimester Screens | | | | | | | Total |
|-----------------------------------|-------|------------------------------------|--------------|-------------|------------|------------|------------|-------------|-------------------------------|
| | | 0 | 1 | 2 | 3 | 4 | 5 | 6+ | |
| Number of First Trimester Screens | 0 | 0 (0%) | 229 (14%) | 68 (4%) | 49 (3%) | 25 (1%) | 23 (1%) | 48 (3%) | 442 (26%) |
| | 1 | 370 (23%) | 46 (3%) | 27 (2%) | 15 (1%) | 12 (1%) | 7 (0%) | 15 (1%) | 492 (30%) |
| | 2 | 140 (9%) | 20 (1%) | 24 (2%) | 7 (0%) | 1 (0%) | 2 (0%) | 7 (0%) | 201 (12%) |
| | 3 | 81 (5%) | 17 (1%) | 5 (0%) | 0 (0%) | 1 (0%) | 1 (0%) | 3 (0%) | 108 (6%) |
| | 4 | 55 (3%) | 12 (1%) | 1 (0%) | 3 (0%) | 0 (0%) | 1 (0%) | 2 (0%) | 74 (4%) |
| | 5 | 35 (2%) | 14 (1%) | 4 (0%) | 2 (0%) | 0 (0%) | 2 (0%) | 7 (0%) | 64 (4%) |
| | 6+ | 150 (9%) | 45 (3%) | 24 (2%) | 18 (1%) | 12 (1%) | 7 (0%) | 47 (3%) | 303 (18%) |
| | Total | 831 (51%) | 383 (23%) | 153 (9%) | 94 (5%) | 51 (3%) | 43 (1%) | 129 (8%) | 1,684 (100%) |

The results presented and discussed here are those pertaining to health care providers' experiences and service provision. The results concerning care providers' knowledge and attitudes are presented elsewhere.²² Forty one percent (41%) of health care providers felt there were characteristics of the patient that effect how they offer prenatal screening tests, 63% preferred to offer first, as opposed to second, trimester screening and 57% felt there were barriers to providing first trimester screening.

Table 2 describes some of the experiences of health care providers with prenatal screening and diagnostic procedures in more detail.

Table 2
Summary of health care provider experiences expressed in percentages

| | GP | GP with postgraduate experience | Obstetrician |
|---|----|---------------------------------|--------------|
| Barriers to providing first trimester screening | | | |
| Cost | 65 | 45 | 8 |
| Timing | 22 | 30 | 62 |
| Distance | 5 | 19 | 15 |
| Difficult to coordinate | 14 | 6 | 8 |
| Characteristics of the patient that effect the way screening is offered | | | |
| Religion | 46 | 39 | 58 |
| Language | 32 | 20 | 25 |
| Education | 18 | 21 | 33 |
| Age | 30 | 30 | 17 |
| SES | 14 | 15 | 25 |
| Cultural beliefs | 16 | 23 | 8 |
| Reasons prefer to offer first over second trimester screening | | | |
| Earlier | 61 | 59 | 36 |
| More accurate | 49 | 41 | 86 |
| Discuss both | 18 | 18 | 7 |
| Discuss results in terms of | | | |
| Increased/not at increased risk | 84 | 86 | 67 |
| Individual risk | 57 | 48 | 63 |
| Age risk | 47 | 40 | 33 |
| Who counsels women following increased risk result | | | |
| Myself | 84 | 91 | 100 |
| Obstetrician | 28 | 15 | 7 |
| Genetic Counsellor | 19 | 13 | 7 |
| Most appropriate action following increased risk maternal serum screen for Down syndrome | | | |
| Amnio | 33 | 74 | 90 |
| Detailed ultrasound | 58 | 21 | 10 |
| Dating ultrasound | 11 | 24 | 20 |
| Refer to GSWA | 33 | 23 | 3 |
| Repeat MSS | 5 | 2 | 0 |

| | GP | GP with postgraduate experience | Obstetrician |
|--|----|---------------------------------------|--------------|
| Most appropriate action following increased risk maternal serum screen for neural tube defect | | | |
| Detailed ultrasound | 58 | 71 | 97 |
| Amnio | 33 | 22 | 10 |
| Refer to GSWA | 33 | 24 | 0 |
| Dating ultrasound | 11 | 12 | 7 |
| Repeat MSS | 5 | 3 | 3 |
| Preferred source of information | | | |
| Written references | 58 | 60 | 57 |
| Laboratory | 52 | 54 | 37 |
| Radiology | 47 | 46 | 57 |
| Colleagues | 42 | 40 | 50 |
| Information sheets | 50 | 49 | 40 |
| Internet | 4 | 2 | 3 |
| CME | 3 | 4 | 7 |
| Obstacles to providing information | | | |
| Constraints in office time | 49 | 48 | 30 |
| Rapidity in advances | 36 | 36 | 23 |
| Lack of patient literature | 30 | 19 | 20 |
| No perceived obstacles | 8 | 14 | 40 |
| Lack of own knowledge | 4 | 4 | 0 |

NB Sections may reach a total of greater than 100% as respondents were allowed to choose more than one option.

In addition, screening tests were introduced as a test available (78%), a test recommended (16%) and as an obligatory test (1%) in pregnancy and by 4% as a precaution because they were at increased risk. Twenty three percent (23%) claimed they rarely explain in depth the conditions that are being screened and 26% claimed they rarely offer women additional information to take home with them.

Thirty one percent (31%) of health care providers discussed results in terms of all three at increased risk / not at increased risk, individual risk and an age risk. Not at increased risk results are communicated by 30% as soon as they are received and by 64% at the next prenatal visit. In terms of at increased risk results, 90% communicate them as soon as they are received and at the next visit by 7%. Eighty eight percent (88%) counsel women with at increased risk results themselves, 20% refer them to an obstetrician and 15% refer them to a genetic counsellor. The average amount of time spent discussing information prior to screening was 11 minutes, following an at increased risk result was 21 minutes and following a not at increased risk result was 5.5 minutes.

Twelve percent (12%) would like to receive additional information on the screening reports, including recommendations (36%), false positive and false negative rates (27%) and sensitivity of the tests (18%). Twelve percent (12%) stated they would like the age risk of the patient omitted.

Health care providers reported that it took significantly longer to receive a second trimester at increased risk ($z = -4.2, p < 0.05$) and not at increased risk ($z = -3.8, p < 0.05$) result as compared to first trimester results (Figure 1).

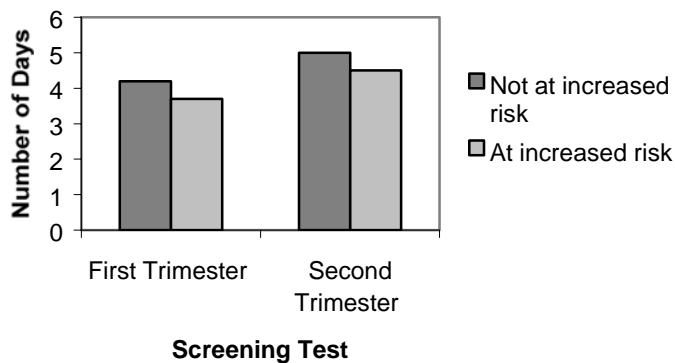


Figure 1 Timing of first and second trimester screening results

The Department of Health (WA) produces a number of resources for both the community and health professionals regarding prenatal screening and diagnostic procedures. Regarding the community resources, 64% of health professionals claimed they had seen them and of these 49% stated they found them either extremely or very useful. Health professionals gave the pamphlets to an average of 59% of the pregnant women they see. A smaller proportion of 30% claimed that the resources for health professionals had been sighted and of these 25% stated they found them either extremely or very useful. Sixty nine percent (69%) had either never attended or attended between one or two educational conferences or workshops where prenatal screening or diagnosis was a significant part of the program.

4 Discussion

International research has established inadequacies in the services provided by health professionals during each stage of the screening and diagnostic process. Their personal values, beliefs and opinions have been shown to impact on this process resulting in the provision of information that is biased and a service that is directive. Limited research has been conducted in the Australian context, however, existing findings illustrate that GPs recognise their need for further guidance in the provision of pre-test counselling. It was the aim of the present study to explore the level of services provided by health professionals and to identify their informational needs with regard to prenatal screening and diagnostic procedures. More specifically, to examine what services are provided, what information and support is given to patients and what current sources care providers are using to gather their own genetic information.

The vast majority of health care providers stated that they offered prenatal screening to all pregnant women. For some health care providers this was due to legal reasons rather than the perception that it was worthwhile. For example,

Offer of screening is done frequently for medico legal reasons rather than because I believe it is a useful or "good" test.

Public knowledge of first trimester screening means that if you don't (offer the test) they want to know why.

However, a smaller 10% indicated that they only offered it to women who met certain criteria, for example, those of advanced maternal age, those with a history of a condition in the family, those who requested it and those who would consider a termination. Additional comments included:

I do not encourage patients to proceed if they would not terminate on the results.

GPs are less likely to offer the tests if they believe the patient is unlikely to have genetic problems/termination of pregnancy.

I oppose abortions, as all my patients know...I hold life sacred and my patients are aware of my beliefs.

I discuss the issue, if they would not countenance abortion I advise not to proceed.

These results are similar to those found by Carroll et al.¹ where health care providers were more likely to offer screening to those women who presented as increased risk, for example, due to

advanced maternal age. Similarly, Yankowitz et al.⁶ and Hunter et al.⁷ found that health professionals were more likely to offer screening when termination was accepted as an option.

When the tests were offered to women, the majority of health care providers introduced them as a test available in pregnancy. However, for close to a quarter of respondents the tests were either recommended or introduced as obligatory. Often this is a vulnerable time for women and as a result women may look to their health care provider for advice as to which tests they should undergo, they may view that ‘doctor knows best’. Because of this vulnerability, it is important that health care providers endeavour to ensure that a woman’s choice is informed. While women may be seeking advice, doctors need to provide non-directive information. They need to ensure that women are aware of all the prenatal tests available, the tests’ costs and benefits and the implications of their choice.

Close to two thirds of health care providers preferred to offer first as opposed to second trimester screening. The unprompted responses indicated that this was due to the test being performed earlier and it was also viewed as a more accurate test. As one GP commented, “if termination is required then early rather than late is easier both medically and emotionally”. Although viewed as the preferred test, 57% of respondents indicated that there were barriers to providing first trimester screening. These included cost, timing, where the women presented too late, the travelling distance required to access the service and the difficulty associated with its coordination.

Further comments illustrated that health care providers were struggling with the offering or discussing of prenatal screening when it was perceived to be inconsistent with their own beliefs or morals:

I currently feel constrained to discuss matters ie. prenatal screening with patients – I take major objection to the ethos. I fail to see how on one hand a child with Down syndrome can be cared for to the best of ability and another can be terminated on whim of parents.

The whole issue of prenatal tests that have significant false positives and negatives is still a difficult issue and then offering termination of pregnancy at 19-20 weeks is a real moral issue.

It is important that health care providers are aware of their own beliefs and attitudes when offering and explaining procedures so that their impact on service provision is minimised.

Other health care providers found the area of prenatal screening and diagnosis to be a difficult and frustrating area as the following comments illustrate.

Many women have pregnancy diagnosed/confirmed and you then have to launch into a detailed discussion about abnormal/choice of tests, etc. to give time to consume it all before they make a decision. All very negative at what should be exciting/happy time. Still very difficult to discuss moderate increased risk results.

People want answers in black and white, but we can only present shades of grey. Nothing is certain in medicine even less so in this area.

The anxiety caused by telling a woman the fetus is at increased risk to be very high despite reassurance most will be normal. I have wondered whether this triple test is worth doing for everyone as it seems to generate so much anxiety when abnormal

A number of other obstacles to providing information to patients was identified. For example, a third of health care providers felt it was difficult to keep up with the rapidly advancing area of genetic testing. Similarly, a small number of GPs identified that their own lack of knowledge restricted their ability to provide women with pre-test information.

Additionally, health care providers felt there were constraints in office time to adequately address women's concerns. Despite comments by health care providers that "the extra time and effort required should be recognised by government" and that "it needs to be acknowledged that a lot of additional time is required to clearly counsel patients on the meaning and results of tests", the survey results indicated that an average of only 11 minutes was spent discussing information with women prior to testing. This equates to the average appointment length, which is inadequate. As one health care provider points out, "the large number of things to discuss at the first antenatal visit makes me wonder how much of the counselling is understood or remembered by most patients". It is suggested that women be given more time to absorb information, perhaps offered a follow-up before they make a decision to have the tests. Although it is acknowledged that it would involve additional time and effort, it is vitally important that women understand the information they are given.

In addition, health care providers selected a lack of patient-oriented-literature as a barrier to providing patients with screening information and a quarter claimed they rarely offer women additional information to take home with them. However, two thirds of health care providers claimed that they had seen specific resources produced by the Department of Health for the

community on prenatal procedures and a third claimed they had seen the resources for health professionals. Furthermore, the majority felt the resources were either useful or extremely useful and health care providers claimed they would give the pamphlets to an average of 59% of the patients they see. A number of health care providers also indicated that Internet availability of the resources would be helpful. Although not directly accessible on the Internet, the pamphlets have recently been made available for ordering via the Internet. It is anticipated this will assist in health care providers' awareness of resources and their uptake. Health care providers further indicated that an algorithm would also be helpful to remind them of the availability and timing of tests.

Health care providers reported that it took them significantly longer to receive second trimester screening results. Given that first trimester screening involves the collaboration between the ultrasound and biochemistry departments, it is interesting that it takes longer for health care providers to receive second trimester screening results, which involves liaison with only biochemistry. Given the anxiety experienced by women in waiting for test results it would be of benefit to investigate the differences in timing. Following an increased risk second trimester maternal serum screen result for Down syndrome, respondents indicated that the most appropriate action in their practice was to offer a dating ultrasound (if not already done), an amniocentesis and/or a referral to Genetic Services of WA for genetic counselling. Following an increased risk second trimester maternal serum screen result for a neural tube defect, respondents indicated that the most appropriate action in their practice was to offer a detailed ultrasound and/or a referral to Genetic Services of WA. In addition, 25% of GPs and 10% of obstetricians believed an amniocentesis was also appropriate in this situation. However, an amniocentesis is used to detect chromosomal abnormalities, such as Down syndrome, by testing the amniotic fluid, and not structural abnormalities, such as a neural tube defect. In this case, a detailed ultrasound would be the most appropriate action.

With regard to the representativeness of the sample it is important to note that we invited health care providers to return the survey if they were seeing pregnant women on a regular basis. Hospital and clinical data indicated that approximately 1625 GPs are ordering prenatal screening

tests. Of these, 75% are ordering less than six first and/or second trimester screening tests per year. This number is likely to be an overestimate, as the search was conducted by provider number, however, it could be argued that this 75% did not respond to the survey, as they do not see pregnant patients on a regular basis.

However, currently in Western Australia between 30% and 40% of women choose not to undertake screening.²³ The health care providers seeing these women may be providing prenatal information, however, as the women chose not to undertake testing, the health care provider would not be ordering the test. It is unclear whether these health care providers are being included in the 1625 sample. They may, however, have been included in the current sample, as those who are seeing pregnant women on a regular basis were invited to participate regardless of whether they were actually ordering prenatal tests. It is uncertain, therefore, the extent to which the current sample is representative of those health care providers in Western Australia (WA) currently seeing pregnant patients on a regular basis.

This argument aside, it is concerning that 75% of health care providers are ordering such a small number of screening tests. It is unlikely that these health professionals will have the experience or knowledge of prenatal screening to provide women with adequate pre- and post-test counselling that would allow her to make an informed decision about the tests. The following comments of respondents in the current sample indicate that there is a lack of education on prenatal screening particularly for the GPs:

The educational roll out to GPs for first trimester screening was a bit slow. I had to ring up a specialist to learn about it

Inconsistent advice to GPs from specialists, eg. Radiology, Obstetricians, gynaecologists, tertiary hospitals and journals I've read, regarding what should be offered

There was no dissemination of info re first trimester screening to GPs. I learnt about it from an obstetrician colleague...a lot of women have missed the opportunity to have these tests

I try to discuss prenatal screening with obstetricians, specialists and colleagues, but the answers I receive only make me more confused which suggests they too are confused

When health care providers were asked about preferred sources of antenatal information for themselves, the primary preference was cited as written references, including journals and books, followed by the laboratory, radiology and colleagues. These results and comments illustrate that

health care providers are approaching their specialist colleagues for information on prenatal procedures. However, as the comments indicate, this is resulting in the sharing of inconsistent information, confusion and uncertainty.

Furthermore, our results indicated that 69% of respondents had either never attended or attended between one or two educational workshops or conferences in their professional lifetimes where prenatal screening or diagnosis was a significant part of the program. It is unclear whether this is due to a lack of availability of workshops, a lack of awareness in the health care provider of professional development or a failure in their uptake of workshops. Additional comments made by health care providers suggest that the former two suggestions are most likely. For example, comments such as “Workshops (would) probably (be) worthwhile as so many tests are available now” and “More seminars and workshops please” were typical of the number of comments made by providers on this topic. We suggest that an investigation into the number of professional development activities available in WA should be undertaken. Following this, efforts should be made to increase their availability and uptake and care providers’ awareness.

Following an increased risk result, the majority of health care providers are likely to counsel women themselves. This is concerning given the lack of experience in prenatal testing, the sharing of inconsistent information and reduced attendance at continuing medical education. However, it is important that health care providers are able to provide counselling, thus it is evident that the provision of professional development by health professional educators remains an area of urgency. In order for health professionals to offer consistent and accurate information to women, they need to receive equivalent information.

It was the aim of this study to explore the level of services provided by health professionals and to identify their informational needs with regard to prenatal screening and diagnostic procedures. More specifically, to examine what services are provided, what information and support is given to patients and what current sources care providers are using to gather their own genetic information. It was identified that according to self-reports, the majority of health care providers were likely to offer screening to all pregnant women and when offered they were

often introduced as recommended. Those practicing in rural areas identified significant difficulties in offering testing due to the travelling distance required. Comments indicated that health care providers face some frustration in offering testing particularly when it is perceived as inconsistent with their beliefs.

It seems that women may be receiving inadequate information due to the lack of experience of some health care providers and minimal continued medical education. It is proposed that workshops and conferences are promoted, an algorithm is investigated and the avenues identified as preferred sources of antenatal screening information are utilised as possible options for care provider education. Furthermore, this education should include practical information that is relevant for health care providers on a day-to-day basis. In addition, efforts should focus on informing health professionals where they can find information when it is needed.²⁰ Furthermore, increased community education and awareness may encourage health professionals to increase their own knowledge levels and encourage them to provide women with comprehensive and accurate information.

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Appendix I

Members of the Reference Group

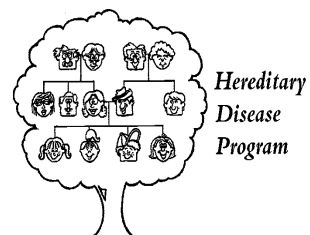
| | |
|-----------------------------|---|
| Dr Bev Hewitt | Ultrasound Specialist Park Ultrasound |
| Assoc Prof Jan Dickinson | University Department of Obstetrics and Gynaecology King Edward Memorial Hospital |
| Dr John Bates | Royal Australian and New Zealand College of Obstetrics and Gynaecology |
| Assoc Prof Carol Bower | Birth Defects Registry King Edward Memorial Hospital |

Appendix II

Hereditary Disease Program
Department of Health

Prenatal Screening and Diagnosis Health Professional Survey

November 2001



The following survey relates to "prenatal screening" and "prenatal diagnostic" procedures, which are carried out during pregnancy to detect fetal anomalies, such as Down syndrome and neural tube defects (e.g. spina bifida).

1. Do you see pregnant patients on a regular basis?

- No => Please skip to question 82 on page 9
 Yes => Please continue

2. How many pregnant patients do you see per year? Av = 73.43

ATTITUDES

In this section we are interested in your attitudes towards fetal prenatal screening and diagnostic procedures. Please indicate the extent to which you agree or disagree with the statement by circling the relevant number for each question.

| | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
|--|----------------|-------|----------------------------|----------|-------------------|
| Example Summer is the best time of year. | 1 | 2 | 3 | 4 | 5 |
| Your Answer(s) | | | | | |
| 3. Fetal prenatal screening tests are valuable. | 45% | 47% | 6% | 1% | 0% |
| 4. Prenatal screening tests benefit pregnant women. | 36% | 48% | 13% | 2% | 0% |
| 5. All pregnant women should have prenatal screening tests. | 12% | 17% | 21% | 36% | 14% |
| 6. Too many "normal" pregnancies are identified as <i>at increased risk</i> . | 3% | 29% | 34% | 29% | 4% |
| 7. Too many "abnormal" fetuses are missed. | 1% | 6% | 34% | 53% | 5% |
| 8. Women should undergo prenatal screening tests only if they plan on terminating an affected fetus. | 11% | 25% | 13% | 39% | 12% |
| 9. Prenatal screening / diagnosis causes too much anxiety for women and their families. | 3% | 13% | 32% | 46% | 7% |
| 10. Educating women regarding prenatal screening and diagnostic tests reduces their anxiety. | 25% | 58% | 9% | 7% | 1% |
| 11. I feel comfortable personally providing my patients with counselling for prenatal tests. | 30% | 62% | 6% | 2% | 0% |

| | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
|---|----------------|-------|----------------------------|----------|-------------------|
| 12. I prefer to refer patients for counselling for prenatal tests. | 1% | 4% | 13% | 59% | 22% |
| 13. Counselling for prenatal tests is too time consuming. | 2% | 14% | 21% | 54% | 1% |
| 14. Counselling should not be required before the test, rather it should be done only when the results are positive. | 1% | 3% | 4% | 43% | 48% |
| 15. I understand the results provided by the first trimester screening report. | 25% | 66% | 5% | 2% | 1% |
| 16. I feel confident conveying this first trimester information to my patients. | 24% | 64% | 7% | 3% | 1% |
| 17. I feel confident in discussing with my patients, choices following first trimester screening results. | 23% | 65% | 6% | 3% | 1% |
| 18. It is difficult to coordinate first trimester screening and follow-up services. | 4% | 14% | 21% | 49% | 10% |
| 19. Follow-up services (e.g genetic counselling) for women with <i>at increased risk</i> first trimester screening results are readily available in my district. | 10% | 44% | 13% | 22% | 10% |
| 20. I understand the results provided by the second trimester screening report. | 24% | 67% | 6% | 2% | 1% |
| 21. I feel confident conveying this second trimester information to my patients. | 24% | 67% | 5% | 4% | 1% |
| 22. I feel confident in discussing with my patients, choices following second trimester screening results. | 24% | 63% | 8% | 5% | 1% |
| 23. It is difficult to coordinate second trimester screening and follow-up services. | 2% | 12% | 21% | 55% | 9% |
| 24. Follow-up services (e.g genetic counselling) for women with <i>at increased risk</i> second trimester screening results are readily available in my area. | 10% | 46% | 14% | 22% | 8% |
| 25. I do not feel comfortable discussing termination issues with my patients. | 4% | 9% | 8% | 51% | 28% |
| 26. More information on the best way to present results to patients would be helpful. | 6% | 45% | 34% | 14% | 1% |
| 27. I feel the need for greater information in the area of prenatal screening. | 6% | 37% | 33% | 22% | 2% |
| 28. I feel the need for greater information in the area of prenatal diagnosis. | 6% | 44% | 31% | 18% | 1% |
| 29. Women should sign written acknowledgment that education about prenatal screening/diagnosis was received before the test is ordered. | 3% | 12% | 30% | 44% | 11% |

EXPERIENCE

In this section we are interested in your experience with fetal prenatal screening and diagnostic tests.

30. Are there any characteristics of the patient that effect how you offer prenatal screening tests? (i.e. religion, language, socioeconomic status)

Yes 41% No 56%

Describe _____

31. To which pregnant women do you offer prenatal screening? (Please tick one)

All pregnant women 91% Only to women who request it 2%

Only to women older than 35 at due date 2% Only to women who would consider a termination 4%

Only to women with a family history of Down syndrome or neural tube defect 1% Other (Please describe)

32. How do you first introduce the screening test to your patients?

As a test available in pregnancy 78% As a precaution because they are *at increased risk* 4%

As a test recommended in pregnancy 16% Other (Please explain)

As an obligatory test in pregnancy 1%

33. Do you prefer to offer first, as opposed to second, trimester screening ?

Yes 63% No 19% No Opinion 17%

Explain _____

34. In your experience, are there any barriers to providing first trimester screening?

Yes 57% No 41%

Describe _____

For the following please indicate the extent to which you agree or disagree with the statement by circling the relevant number for each question.

| | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
|--|-----------------------|--------------|-----------------------------------|-----------------|--------------------------|
| 35. I always stress to my patients that tests are voluntary. | 50% | 44% | 4% | 2% | 0% |
| 36. I always explain the procedure of screening and/or diagnosis. | 41% | 55% | 3% | 0% | 0% |
| 37. I always explain the purpose of screening and/or diagnosis. | 44% | 55% | 0% | 0% | 0% |
| 38. I rarely make clear the implications of results. | 4% | 4% | 7% | 52% | 31% |
| 39. I always explain the risks associated with diagnosis. | 29% | 58% | 7% | 4% | 2% |
| 40. I rarely explain in depth the conditions that are being screened for. | 2% | 21% | 22% | 45% | 11% |
| 41. I always inform the patient of the possibility of false positives / false negatives. | 31% | 56% | 8% | 5% | 1% |
| 42. I always explain the sensitivity of the tests beforehand. | 21% | 50% | 19% | 8% | 1% |
| 43. I rarely offer additional information for the patients to take home with them. | 4% | 22% | 15% | 41% | 18% |
| 44. I always offer follow-up appointments to women to allow for information to be absorbed and for further questions, before a decision is made. | 13% | 50% | 17% | 17% | 2% |

At present, the following information is included on both the first and second trimester screening report:

- Whether the patient is *at increased risk* / *not at increased risk***
- An individual risk**
- An age risk**

45. Is there any additional information you would like to receive on these reports?

46. I discuss results with my patients in terms of:

- | | | | |
|--|------------------------------|----------------------------------|------------------------------|
| At increased risk / not at increased risk | <input type="checkbox"/> 84% | An age risk | <input type="checkbox"/> 42% |
| An individual risk | <input type="checkbox"/> 53% | Other (<i>Please describe</i>) | <input type="checkbox"/> |
| | | _____ | |
| | | _____ | |

47. When I communicate *AT INCREASED RISK* results to women:

- | | | | |
|---------------------------------------|------------------------------|---|--------------------------|
| I do so as soon as I receive them | <input type="checkbox"/> 90% | <i>At increased risk</i> results are <u>not</u> communicated | <input type="checkbox"/> |
| I do so at the next prenatal visit | <input type="checkbox"/> 7% | Other (<i>Please describe</i>) | <input type="checkbox"/> |
| | | _____ | |

48. When I communicate *NOT AT INCREASED RISK* results to women:

- | | | | |
|---------------------------------------|------------------------------|---|-----------------------------|
| I do so as soon as I receive them | <input type="checkbox"/> 30% | <i>Not at increased risk</i> results are <u>not</u> communicated | <input type="checkbox"/> 1% |
| I do so at the next prenatal visit | <input type="checkbox"/> 64% | Other (<i>Please describe</i>) | <input type="checkbox"/> 3% |
| | | _____ | |

49. In most cases prior to screening, who in your practice discusses the majority of screening information with pregnant women?

- | | | | |
|--------------------|------------------------------|---|--------------------------|
| Myself | <input type="checkbox"/> 96% | Screening information is not discussed prior to screening | <input type="checkbox"/> |
| Midwife | <input type="checkbox"/> 2% | | |
| Genetic counsellor | <input type="checkbox"/> | Other (<i>Please specify</i>) | <input type="checkbox"/> |
| Clinic nurse | <input type="checkbox"/> | _____ | |

50. Who counsels women with *at increased risk* results?

- | | | | |
|--|------------------------------|---------------------------------|--------------------------|
| Myself | <input type="checkbox"/> 88% | Counselling is not offered | <input type="checkbox"/> |
| An Obstetrician (other than yourself if you are an Obstetrician) | <input type="checkbox"/> 20% | Other (<i>Please specify</i>) | <input type="checkbox"/> |
| | | _____ | |
| A Genetic Counsellor | <input type="checkbox"/> 15% | _____ | |

51. Please estimate the total time per patient that is spent discussing information:

- Prior to screening Av = 11 minutes
- Post screening (following an *at increased risk* result) Av = 21 minutes
- Post screening (following a *not at increased risk* result) Av = 5.5 minutes

52. From the time the ultrasound is performed or the blood is collected, on average, how long does it take to receive a first trimester not at increased risk result? Av = 4.2 days

53. From the time the ultrasound is performed or the blood is collected, on average, how long does it take to receive a first trimester at increased risk result? Av = 3.7 days

54. From the time the blood is collected, on average, how long does it take to receive a second trimester not at increased risk result? ___ Av = 5.0 ___ days

55. From the time the blood is collected, on average, how long does it take to receive a second trimester at increased risk result? ___ Av = 4.5 ___ days

56. If second trimester screening results show *at increased risk* for Down syndrome, the most appropriate action at my practice is to offer:

- | | | | |
|---------------------------------|------------------------------|---|------------------------------|
| Amniocentesis | <input type="checkbox"/> 74% | Dating ultrasound (if not already done) | <input type="checkbox"/> 22% |
| Detailed ultrasound | <input type="checkbox"/> 20% | Refer to Genetic services of WA | <input type="checkbox"/> 24% |
| Repeat maternal serum screening | <input type="checkbox"/> 4% | Ignore the result | <input type="checkbox"/> |

57. If second trimester screening results show *at increased risk* for a neural tube defect (raised AFP), in my practice the most appropriate action is to offer:

- | | | | |
|---------------------------------|------------------------------|---|------------------------------|
| Amniocentesis | <input type="checkbox"/> 25% | Dating ultrasound (if not already done) | <input type="checkbox"/> 11% |
| Detailed ultrasound | <input type="checkbox"/> 67% | Refer to Genetic Services of WA | <input type="checkbox"/> 26% |
| Repeat maternal serum screening | <input type="checkbox"/> 4% | Ignore the result | <input type="checkbox"/> |

58. What is the preferred source of antenatal screening information for yourself? (Please rate your top 3 e.g. 1 = highest preference to 3 = third highest preference)

- | | | | |
|---------------------------------------|--------------------------|--------------------------------|--------------------------|
| Laboratory | <input type="checkbox"/> | Newspaper | <input type="checkbox"/> |
| Radiology or Ultrasound | <input type="checkbox"/> | Information sheets / pamphlets | <input type="checkbox"/> |
| Written reference eg journal / books, | <input type="checkbox"/> | Internet | <input type="checkbox"/> |
| Colleagues | <input type="checkbox"/> | Other (Please describe) | <input type="checkbox"/> |
| | | _____ | |
| | | _____ | |

59. What is the greatest obstacle to providing patients with information on genetic issues?

- | | | | |
|--|------------------------------|--------------------------------------|------------------------------|
| Rapidity of advances in testing for genetic diseases. | <input type="checkbox"/> 34% | Lack of patient oriented literature. | <input type="checkbox"/> 24% |
| Constraints of office time to adequately address women's genetic concerns. | <input type="checkbox"/> 47% | Other (Please describe) | <input type="checkbox"/> |
| | | _____ | |
| | | _____ | |
| No perceived obstacles | <input type="checkbox"/> 14% | _____ | |

KNOWLEDGE

In this section we are interested in what you know with regards to fetal prenatal screening and diagnosis. **IT IS NOT A TEST. REMEMBER ALL ANSWERS ARE ANONYMOUS.**

60. How would you rate your knowledge of prenatal screening?

Very Good 7% Good 35% Adequate 52% Poor 3% Inadequate 1%

61. How would you rate your knowledge of prenatal diagnosis?

Very Good 6% Good 30% Adequate 55% Poor 6% Inadequate 1%

62. Following a screening test, what percentage of women receive an *at increased risk* result? (Please tick one)

1% 28% 10% 10%
5% 53% 15% 2%

63. Which of the following are risk factors for passing on hereditary conditions? (Please tick all that apply)

Maternal age 66% This is the first child 2%
Weight 3% The woman has had more than two miscarriages 46%
Family history of the condition 98% Smoking 10%
Partners that are close relatives 86% Exercise

64. When is the optimal time for first trimester screening to take place?

9-10 weeks 9% 12-15½ weeks 3%
11½ -13 weeks 84% 15-17 weeks

65. When is the optimal time for second trimester screening to take place?

9-10 weeks 12-15½ weeks
11½ -13 weeks 12% 15-17 weeks 84%

For the following statements, please indicate with a tick whether you believe they are “True”, “False” or you’re “Unsure”.

| | True | False | Unsure |
|--|-------------|--------------|---------------|
| 66. A birth defect occurs in 5% (1 in 20) of all pregnancies. | 65% | 20% | 12% |
| 67. Most women (98%) who receive an <i>at increased risk</i> result have healthy babies. | 71% | 13% | 12% |
| 68. If a <u>first</u> trimester screening test shows <i>at increased risk</i> , further tests can be done to clarify a diagnosis. | 93% | 1% | 3% |
| 69. <u>Second</u> trimester maternal serum screening detects only Down syndrome. | 2% | 93% | 2% |
| 70. <u>Second</u> trimester maternal serum screening is routine for all pregnant women. | 11% | 84% | 2% |
| 71. If <u>second</u> trimester maternal serum screening shows <i>at increased risk</i> , further tests can be done to clarify a diagnosis. | 95% | 2% | 0% |
| 72. Women who have normal second trimester maternal serum screening results can be certain that they will have a healthy baby. | 2% | 96% | 1% |
| 73. Prenatal screening tests pick up 100% of abnormalities. | 0% | 97% | 0% |
| 74. If an <i>at increased risk</i> result is given this means the fetus definitely has Down syndrome or a neural tube defect. | 1% | 96% | 0% |
| 75. Amniocentesis and fetal karyotyping can clarify the existence of Down syndrome. | 96% | 1% | 0% |
| 76. Amniocentesis is routinely offered to women aged 35 to 37 years or older. | 50% | 41% | 6% |
| 77. Folic acid is important in preventing 70% of neural tube defects. | 93% | 2% | 3% |
| 78. The best time to start taking folic acid is as soon as the pregnancy is confirmed. | 7% | 91% | 0% |
| 79. The results of chorionic villus sampling are 99% accurate. | 65% | 11% | 22% |
| 80. A negative result from a chorionic villus sampling guarantees the absence of all birth defects and/or hereditary conditions. | 2% | 86% | 9% |
| 81. There is a chance of miscarriage associated with chorionic villus sampling and amniocentesis. | 97% | 0% | 0% |

BACKGROUND

The following questions ask for general background information.

82. Had you heard of the Department of Health's Hereditary Disease Program before today?

Yes 66% Not sure 6%
No 26%

83. Have you seen the Hereditary Disease Program's pamphlets on prenatal screening and diagnosis for women?

Yes 64% Not sure 16%
No 18%

If so, how useful do you find them?

| | | | | |
|------------------------------|------------------------------|------------------------------|-----------------------------|-----------------------------|
| Extremely Useful | Very Useful | No opinion | Not very useful | Useless |
| <input type="checkbox"/> 12% | <input type="checkbox"/> 37% | <input type="checkbox"/> 13% | <input type="checkbox"/> 5% | <input type="checkbox"/> 0% |

To what proportion of pregnant women do you give the pamphlets? Av = 59 %

What changes would you suggest for the pamphlets?

84. Have you seen the Hereditary Disease Program's fact-sheets for health professionals?

Yes 30% Not sure 29%
No 38%

If so, how useful do you find them?

| | | | | |
|-----------------------------|------------------------------|------------------------------|-----------------------------|-----------------------------|
| Extremely Useful | Very Useful | No opinion | Not very useful | Useless |
| <input type="checkbox"/> 4% | <input type="checkbox"/> 21% | <input type="checkbox"/> 11% | <input type="checkbox"/> 2% | <input type="checkbox"/> 0% |

What changes would you suggest for the fact-sheets?

85. What is your year of birth? Av = 43.5 years

86. What is your gender?

Male 50% Female 50%

87. In what postcode is your workplace situated? Metro = 69%, Rural = 24%

88. What is your highest qualification? *(Please tick one)*

Obstetrician 9% General Practitioner 40%

Other Specialty _____ General Practitioner with 50%
postgraduate qualifications
(eg Dip Obstetrics)

89. What year did you graduate with this qualification? Av = 15.3 years previous

90. Since graduating, how many educational conferences or workshops have you attended in which prenatal screening or diagnosis was a significant part of the program?

None 26%

1 or 2 43%

≥3 24%

Can't recall 5%

Please feel free to write any other comments you may have regarding your experience with prenatal screening and diagnostic procedures or this survey.

Appendix III

Dear GP/Obstetrician,

You have been selected to take part in a short survey, which asks you about your experience with prenatal screening and diagnostic tests; it should take no more than 15 minutes to complete.

The Hereditary Disease Program at the Department of Health was established to provide information to the Western Australian community and professionals, to raise awareness of hereditary conditions and birth defects. To achieve this, we need to know more about health professionals' knowledge, attitudes and the services provided in relation to prenatal screening and diagnostic procedures.

By returning the **enclosed** survey you will be providing valuable information that will help the Hereditary Disease Program improve our services for health professionals.

The survey is completely voluntary and confidential. This means that you may withdraw your information at **any** time. Your responses will remain **ANONYMOUS**, as there is **NO** identifying information on the survey. As a result, you can feel free to answer the questions openly and honestly.

A pre-paid, addressed envelope is included. Please return the survey in this envelope by **Friday 30th November 2001**. Your return of the completed survey is deemed consent to participate.

If you have any questions please do not hesitate to contact me, Kristie Rostant. Alternatively, if you would like any further information regarding prenatal screening or diagnostic tests please contact the program on telephone (08) 9222 4436 or e-mail hdphelp@health.wa.gov.au.

The current research has been approved by Curtin University's Human Research Ethics Committee.

Once again, thank you for your help in completing this survey. We look forward to receiving your valuable comments.

Yours sincerely

Kristie Rostant
Coordinator
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Dr Peter O'Leary
Program Manager
Hereditary Disease Program

Appendix IV

Dear GP / Obstetrician

RE: Prenatal Screening and Diagnosis – Health Professional Survey

You may remember receiving a survey during November of last year (2001) from the Department of Health WA. We understand that your lives are extremely busy and you are often invited to participate in a number of surveys from various parties throughout the year.

As we assured confidentiality and anonymity, we cannot determine who has and who has not returned the survey. If you have already returned it, we thank you very much for your participation and please disregard this notice.

However, only 24% have been returned. We would like you to return the survey even if you are not seeing pregnant women on a regular basis or if you are retired. If you have not returned the survey there is still time to send it in!

Please also keep in mind that in order for our program to assist health professionals with their educational needs we need to hear from you directly. There is added advantage in our program generating informational resources or organising seminars in this area for health professionals with your input, so if you feel that this is important we urge you to participate.

We need to know how we can help you!

It is completely voluntary, but we would also really value your input, so if you want to participate please send it in as soon as possible. If you need a new copy of the survey, any other information or had any further questions please do not hesitate to contact us.

Thanking you again.

Sincerely,

Kristie Rostant
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Public Health Genomics Branch
(Previously Hereditary Disease Program)
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E-mail: Kristie.Rostant@health.wa.gov.au

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11 March 2002