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Running Head: PRENATAL SCREENING AND DIAGNOSIS

A survey of the knowledge, attitudes and experiences of Western Australian women in relation to prenatal screening and diagnostic procedures.

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## Abstract

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The aim of the present study was to determine the availability of information to Western Australian women, regarding prenatal procedures and subsequently determine their knowledge, attitudes and experiences in this area. The participants were 633 women aged 15 to 45 years who replied to a self-administered mail survey. Results were analysed in terms of the dependant variables, of knowledge and attitudes, and the demographic details, of age, education, health cover, geographical area, having or not having the tests and access to information. The mean total knowledge score was 16 out of a possible 26 (62%). The average score for all three attitude factors was four, “agree”, on a likert scale of five. Knowledge, attitude towards the adequacy of information, confidence in results, number of pregnancies and the number of children all significantly positively correlated with age. Private patients, patients in the metropolitan area and those who reported seeing prenatal information had significantly higher knowledge levels and had significantly more positive attitudes towards the adequacy of information, than public patients, patients in rural areas and those who reported not seeing prenatal information, respectively. In addition, private patients and those who reported seeing prenatal information were also found to be significantly more confident in their test results than public patients and those who reported not seeing prenatal information. Those who did not have a screening test had greater knowledge, less positive attitudes towards the adequacy of information, the value of the tests and confidence in results, than those who did undergo screening. Those with higher educational attainments had higher knowledge and more positive attitudes towards the value of the tests than those with lower educational attainments. Overall, women felt the tests were valuable, however it was clear they need more support, information, explanations, and more time to absorb the information.

## Table of Contents

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Acknowledgments.....	ii
Abstract.....	iii
<a href="#">Introduction</a> .....	1
<a href="#">Method</a> .....	6
<a href="#">Participants</a> .....	6
<a href="#">Measures</a> .....	7
<a href="#">Procedure</a> .....	7
<a href="#">Results</a> .....	8
<a href="#">Discussion</a> .....	12
<a href="#">References</a> .....	19
Appendices.....	21
Appendix I: Prenatal Screening and Diagnosis – Survey of New Mothers	
Appendix II: Members of the Reference Group	
Appendix III: Participant’s Covering Letter	

## List of Tables and Figures

---

Table 1	Comparison of Population and Sample Demographics	6
Table 2	Reasons for Choosing to Have Prenatal Tests	8
Table 3	Reasons Against Choosing to Have Prenatal Tests	9
Figure 1	Mean knowledge scores for each level of educational attainment	10
Figure 2	Mean attitude scores towards the value of the tests for each level of educational attainment	11

## Introduction

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Prenatal screening procedures are options available to women in both the first (11-13 weeks) and second trimesters (14-18 weeks) of pregnancy. Screening procedures are noninvasive tests aimed at identifying those *at increased risk* of birth defects and/or hereditary conditions, such as Down syndrome, neural tube defects (NTD) and some other fetal anomalies. Women should understand the implications and limitations of each test in order to make an informed choice about whether or not they should be undertaken. For this reason, pre-test counselling by the provision of information is an important preliminary step. Women who are identified as being *at increased risk* are offered the option of undertaking a diagnostic procedure, such as chorionic villus sampling (CVS) or amniocentesis. Diagnostic procedures are invasive tests that carry a risk of miscarriage and can confirm, with 99% accuracy, the presence of a chromosomal abnormality. If such a condition is diagnosed the couple should be counselled in regard to characteristics and implications of the condition, as well as choices available, such as termination. Due to the contentious and moral nature of the topic, prenatal procedures remain areas of high interest and debate. Furthermore, they confront women with some difficult decisions and place increased importance on the availability of information.

There has been some debate regarding the decision-making process in relation to these procedures. For example, the process has been previously understood in terms of the autonomy model whereby it is assumed that individuals are independent beings that, once provided with information, are transformed into knowledgeable and empowered decision-makers [1]. This model, however, has been challenged especially in context of the present topic. Various constraints are recognised that do not allow a totally autonomous decision-making process to take place [2]. The process in regard to genetic screening and diagnosis may also be influenced by other factors [3]. That is, the individual must take into account her attitudes towards the information that has been presented, which may be further influenced by her religious beliefs [4] or beliefs regarding the equality of life [2]. In this regard, the level of importance women place on the outcome of the pregnancy might also affect their final decision to undergo testing. For example, women may forego screening and diagnostic procedures in order to avoid a situation whereby an abnormality may be found further leading to a possible unwanted decision regarding the fate of the unborn fetus [5]. Therefore, while it is clear that accepting that the decision-making process is complex, it nevertheless remains that the availability of information is an important first step to making that decision.

The availability of information on prenatal screening and diagnostic procedures affects the choice made by women of whether or not to undergo testing. In the first instance, a lack of information and a lack of understanding may lead women to refuse a screening or diagnostic procedure [6, 7, 8]. For example, Marteau et al. (1992) performed a study whereby women undergoing maternal serum screening (MSS) and women who refused to have the test were compared on various measures to predict the uptake of the screening procedure. It was found that women in the former group had more knowledge of the test than women in the latter, whereas no differences were found between the two groups on perceptions of either the threat of having a baby with an abnormality or termination. The authors then suggested that in fact, had the latter group been more informed they might have made the decision to undergo the screening procedure.

Contrary to this, higher availability of information and understanding may actually serve to dissuade women from undergoing procedures. That is, after being informed of the limitations of the tests women may choose to decline procedures. For example, screening procedures have been found to have a relatively high (20-30%) false positive rate [9]. Santalahti et al. (1998) found that once women were better informed of this limitation, they were inclined to think more carefully about going through with the procedures, as they wanted to avoid the unnecessary stress that may result from a false positive result. This is illustrated in the following quote by one participant of the study by Press and Browner (1997):

“...So then you get this positive and you're panicked because you think that there is some kind of problem...and if there is no problem you feel better but there's been a lot of undue stress. (But) if there is a problem, well you're already 24 weeks pregnant. So then you have to make a choice and I can't make that choice...So now I've gone through all of this to find out something is wrong but I'm not going to do anything about it anyhow. So then I figure, why am I taking the test?”

This quote further illustrates another limitation, namely the lateness of second trimester diagnosis, and the anxieties that result.

In addition, as mentioned earlier, diagnostic procedures have been found to carry some risk of miscarriage. Again, women might be inclined to refuse such procedures due to this reason [4]. Furthermore, Santalahti et al. (1998) identified that some women did not actually realise the miscarriage risk until afterwards, and in fact had they realised the risk earlier, they would not have undergone the procedures. Moreover, there is a 45% spontaneous loss of Down syndrome affected fetuses between ten weeks gestation and term [11]. Again, once given this information, women might decide that prenatal tests are unnecessary. It can be seen that additional information, in the form of test limitations, may in fact have the power to change a woman's decision regarding the uptake of screening and diagnosis, thus justifying the high importance placed on the informed decision.

Of the women who do decide to undergo screening and diagnostic procedures, it is generally agreed that they see the procedures to be valuable and important [12, 8, 13, 14]. Baillie et al. (2000) conducted semi-structured interviews with 24 pregnant women who had undertaken ultrasound screening and it was found that overall, women expressed positive attitudes towards the screening. However, it was seen to be more of a social, rather than medical event. It was found that in fact women may have little idea as to the actual purpose of the screening whereas knowledge of the actual procedure was a great deal higher [10, 12]. Further to this, Al-Jader et al. (2000) found that many women might not be fully aware that the screening tests are voluntary. In contrast, Marteau, Johnston, Shaw, and Slack (1989) reported that the decision to undergo amniocentesis may be an informed one, as they found that women choosing to undergo the procedure were less likely to be concerned about miscarrying the fetus and undergoing a termination of an affected fetus.

When exploring specifically why women undertake testing, a variety of reasons were identified. Screening tests have been viewed as an opportunity to see the baby and provide some level of assurance that the baby is healthy [10]. Other reasons reported by women included “just needing to know one way or the other” [12], avoiding any possibility of “surprise” that may occur at birth and being able to prepare for what might lie ahead [10, 4]. Furthermore, an ultrasound examination has been identified by women as a “self-evident act”, as one routine test amongst others, in which a woman participates without any special discussion [12].

On the other hand, Press and Browner (1997) found that 85% of respondents who agreed to testing took little time to deliberate before deciding and actually had difficulty articulating precisely why they had accepted. Santalahti et al. (1998) established that only 25% of women opting to participate in prenatal screening, described actively making the decision, despite the fact that in most cases it was presented as voluntary or their option. In the extreme, however, Marteau, Johnston, Plenicar, Shaw, and Slack (1988) found that 29% of women who had serum screening subsequently denied having the test and 16% of the women sampled in the study by Gekas, Gondry, Severine, Cesbron, and Thepot (1999), stated that the test was done without their agreement. Given that it is generally believed that a woman’s choice regarding the above procedures should be informed, it is of concern that women have identified the procedures as “routine” and the choice to be a passive one.

The influence of the health care provider was also found to impact profoundly on the choices made by women. When a test was presented by care providers as standard and routine, and received institutional support, it was accepted without problem or question [7]. In this same study, French et al. (1992) further pointed out that some care providers are directive in

their health care manner, and women may view that the care provider knows what is best for them. In support of this, Gekas et al. (1999) found that for 41.5% of women, serum screening was presented as a mandatory test by the care provider. With regard to diagnosis, women may feel pressured to make a quick decision without full information [18]. Therefore, women may undertake testing purely to conform with the care provider's suggestion.

In addition to adopting a directive manner, Smith, Slack, Shaw, and Marteau (1994b) in an analysis of midwife and obstetrician knowledge levels, found that care providers disclose information that they perceive to be important in the decision-making process of pregnant women. In doing so, care providers can shape women's understanding of the meaning and purpose of screening to be consistent with their own beliefs and views [10].

However, in the study by Smith et al. (1994b) it was reported that knowledge levels were poor in 43% of midwives and 14% of obstetricians. Consistent with this result, Ryder (1999) found that midwives generally felt unprepared in terms of knowledge and understanding about the serum-screening test following its introduction. This lack of knowledge on the part of care providers is further supported by Statham and Green (1993) in an analysis of women's experiences with serum screening. It was found that care providers often hold varying misconceptions with regard to the meaning of the results of screening and diagnostic tests and the interpretation of risk.

As a result, not only are women being provided with inadequate information, but also the information that care providers perceive to be important, may in fact be inaccurate. This lack of, and possible inaccuracy of, pre-screening information means that the objectives of the procedures may be poorly understood, and *at increased risk* results may not be expected. This may subsequently result in high levels of distress, some of which could be avoided [21, 19].

It is probable that the decision-making process regarding the uptake of genetic screening and diagnosis is more complex than purported by the autonomous model. While accepting the concept that there are other facets to the decision-making process, including the consideration of attitudes and beliefs, it remains clear that the availability of information to women about the procedures is an important first step. The availability of information affords increased knowledge and provides the basis for informed and voluntary decisions. As stated by O'Connor et al. (1999), patients first need to understand the options and outcomes in order to determine the personal value they place on the benefits versus the harm.

The Department of Health of Western Australia established an education program in response to the need for information on hereditary conditions. One of its main objectives is to raise awareness within the community of hereditary conditions and their detection. Due to the high importance placed on the availability of information and the varying knowledge levels of

women regarding prenatal screening and diagnosis, the present study aims to determine the availability to Western Australian women, of information regarding these procedures and to subsequently determine their knowledge, attitudes and experiences in this area.

In the recent past the Department of Health distributes educational resources about maternal serum screening, however more recently, new resources targeting prenatal screening and diagnostic procedures have been produced. As a result, in addition to the above aims, the information gained from the present study forms the first phase of a longer-term study. It provides baseline statistics to determine whether its educational objectives are being met and will help to determine whether these recent developments, in regard to service delivery and health promotion, are successful.

## Method

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### Participants

The survey was sent to all women who gave birth during the month of July 2001, excluding those women who gave birth to a stillborn baby and those women who experienced a neonatal death ( $N = 1801$ ). A single month was chosen to obtain a sample, as opposed to a sample from the past 12 months, as women's memories regarding the procedures were likely to deteriorate with time. On the other hand women's memories are naturally poor in the short time following the birth of a child [23] and it was further acknowledged that women need time to settle in at home with their newborn. Thus a period of three to four months was allowed following the birth before administration of the survey. As the survey was to be sent out in October 2001, the month of July 2001 was chosen.

Forty-five surveys were returned as the wrong address, leaving a total possible sample of 1756. Six hundred and thirty three (633) completed surveys were returned, resulting in a response rate of 36%. Demographic information of women, including geographical area and health coverage, was available before mail-out, however no such information was available on educational attainment. To determine the representativeness of the sample, statistics provided by the Australian Bureau of Statistics from May, 2000 were consulted. Table 1 illustrates the differences in demographic statistics between the potential population and the returned sample in relation to geographical area, educational attainment and health coverage.

Table 1.

#### *Comparison of Population and Sample Demographics*

	<b>Population (<math>N = 1801</math>)</b>	<b>Sample (<math>N = 633</math>)</b>
<b>Geographical Area</b>		
Metro	50%	67%
Rural	19%	24%
Missing	31%	9%
<b>Educational Attainment</b>		
Year 10	33%	16%
Year 12	27%	17%
Tafe	16%	24%
University	24%	34%
Missing	0%	9%
<b>Health Coverage</b>		
Public	49%	35%
Private	20%	57%
Missing	31%	8%

As the table demonstrates the sample was more highly educated than the population and is over-represented by women who have private health coverage. Ages ranged from 15 to 45 with the mean age of the sample being 30.8 years.

### Measures

The information of interest was collected via a self-administered mail survey (see [Appendix I](#)) that took approximately 15 minutes to complete. Items included in the survey were constructed following a review of the literature and similar surveys from international studies [24, 3, 16, 14]. Furthermore, a reference group, consisting of health professionals (see [Appendix II](#)), was established in order to provide expertise and to advise on issues, which they identified as warranting particular focus or concern. A final copy of the survey was then recirculated to members of the reference group so that content validity could be established. The survey was piloted on a small number of women to verify ease of understanding. The survey is a 59-item form separated into four sections, experience (eight items), attitudes (18 items), knowledge (26 items) and background information (seven items). The three factors identified in the attitude scale, were found to have adequate internal consistency coefficients ranging from 0.85 to 0.89.

### Procedure

The Midwives' Notification System database at the Department of Health and the King Edward Memorial Hospital was accessed in order to obtain contact and pre-test demographic information of women. The surveys were then mailed out together with a covering letter (see [Appendix III](#)) and a reply paid envelope, following which the contact information was destroyed. A mail survey was chosen as the method of data collection as it is relatively inexpensive to undertake. As the topic is of a relatively sensitive nature a mailed survey, as opposed to a telephone survey, was chosen as the more viable option. Return of the completed survey was deemed consent to participate. Women were also given the option to include their names and contact details on the returned survey should they have wish to take part in a further interview or to request further information.

## Results

It was found that 66% of the women reportedly had ultrasound, 33% had MSS, 9% had amniocentesis and 2% had CVS. Between 2% and 11% stated that they were unsure whether or not they had any of the procedures in question. Twenty two per cent (22%) and 46% stated that they had never heard of MSS or CVS respectively. Twenty nine per cent (29%) stated they had seen information pamphlets; 60% first found out about the tests through their GP or specialist and when introduced to them, the screening tests were referred to as recommended (61%), as a precaution (10%) and as obligatory (8%). Women were asked to choose their three most common sources of information. They were reported as their GP (51%), pamphlets (39%) and their specialist (36%).

In the subsequent analyses, descriptive statistics, generated using multiple response analyses, were conducted to explore the experiences of women with prenatal screening and diagnostic tests. Table 2 illustrates the percentage of women who cited particular reasons for choosing to have prenatal screening and diagnostic tests. Each column reaches a total of greater than 100%, as women were able to choose more than one option.

Table 2.

### *Reasons for Choosing to Have Prenatal Tests*

	Reason for Ultrasound	Reasons for MSS	Reasons for amniocentesis	Reasons for CVS
To make sure the baby was healthy	80%	73%	56%	35%
To see the baby	66%	40%	6%	6%
It's routine	47%	50%	3%	3%
Risk of a condition being passed on	47%	51%	64%	41%
Aged above 35-37 years	17%	16%	56%	6%
It was the care provider's decision	21%	27%	12%	53%
Conformity with care provider's suggestion	32%	37%	25%	35%

Table 3 illustrates the percentage of women who have cited particular reasons for choosing not to have prenatal screening and diagnostic tests. Again women were able to choose more than one response.



Table 3.

*Reasons Against Choosing to Have Prenatal Tests*

	Reasons against ultrasound	Reasons against MSS	Reasons against amniocentesis	Reasons against CVS
It wasn't necessary	40%	55%	72%	51%
Didn't know about them	20%	28%	5%	37%
The risk was too high	29%	17%	15%	8%
Did not want to be faced with an unwanted decision	2%	2%	26%	10%
Not aged above 35-37 years	41%	30%	40%	26%
Was not concerned about passing on a condition	26%	30%	15%	10%

The data was screened for violations to the assumptions of normality using Lilliefors and Shapiro Wilkes statistics for each of the outcome measures. For all of the outcome measures, normality was violated. That is, attitudes towards information, towards the value of the tests and towards the results of the tests, and knowledge were negatively skewed, with skewness statistics of -0.751, -0.774, -0.601 and -0.462 respectively. A natural logarithmic transformation was performed, however normality remained violated for all measures. Thus, the nonparametric techniques of the Kruskal-Wallis test, the Mann-Whitney test and Spearman's Rank-Order Correlation were used.

Analyses were conducted to explore the relationship between the dependant variables, of knowledge and attitudes, and the demographic details of age, education, health cover, geographical area, having or not having the tests and access to information. First, principal component analyses (PCA) were performed using an oblimin extraction on both of the outcome measures to identify significant underlying factors. The PCA for knowledge revealed no reliable factors and as a result a total knowledge score was used. The mean total knowledge score was 16 out of a possible 26 (62%). Eighteen percent (18%) of the sample attained a total score of 50% or below (failed the knowledge questions). The PCA for the attitude scale revealed three reliable factors explaining 69% of the variance. Items with double loadings or those that lacked face validity were removed. The three factors identified were attitude towards the adequacy of information, attitude towards the overall value of the tests and confidence in results. The average score for all three factors was four (agree) on a five-point likert scale.

Neither knowledge nor the attitude factors were correlated with number of children or number of pregnancies. Knowledge ( $r = 0.13$ ), attitude toward the adequacy of information ( $r = 0.16$ ) and confidence in results ( $r = 0.21$ ) were found to significantly increase with age, as were number of pregnancies ( $r = 0.28$ ) and number of children ( $r = 0.29$ ). Significant differences were found between type of health coverage ( $U = 33476, p < 0.05$ ), geographical area ( $U = 28822, p < 0.05$ ) and access to information ( $\chi^2(2) = 10.47, p < 0.05$ ) and knowledge, where access to information comprised of three groups. Private patients, metropolitan patients and those who reported seeing the pamphlets had significantly higher knowledge levels than public patients, rural patients and those who reported not seeing the pamphlets, respectively.

T-tests further indicated that private ( $U = 35655.5, p < 0.05$ ) and metropolitan ( $U = 27288, p < 0.05$ ) patients and those who reported seeing the pamphlets ( $\chi^2(2) = 48.97, p < 0.05$ ) had significantly more positive attitudes towards the adequacy of information. In addition, those who reported seeing the pamphlets ( $\chi^2(2) = 14.25, p < 0.05$ ) were also found to be significantly more confident in their results.

Significant differences were found between undergoing a screening test and knowledge ( $U = 27563, p < 0.05$ ), whereby those who did not have a screening test had greater knowledge than those who did undergo screening. Attitudes towards the adequacy of information ( $U = 26713.5, p < 0.05$ ), the value of the tests ( $U = 23172, p < 0.05$ ) and confidence in results ( $U = 25415, p < 0.05$ ) were found to be greater for those who did undertake screening.

Significant differences were found between levels of education and knowledge ( $\chi^2(3) = 67.75, p < 0.05$ ). Figure 1 suggests that university graduates were more knowledgeable than all other levels of education.

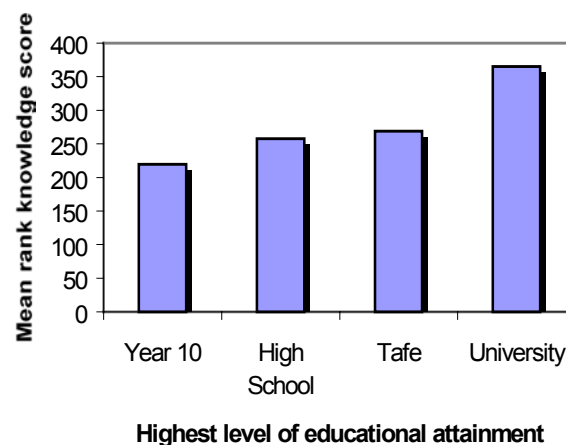


Figure 1. Mean rank knowledge scores for each level of educational attainment.

Significant differences were also found between levels of education and attitude towards the value of the tests ( $\chi^2(3) = 3.68, p < 0.05$ ). Figure 2 suggests that the university graduates were less positive than all other levels of education.

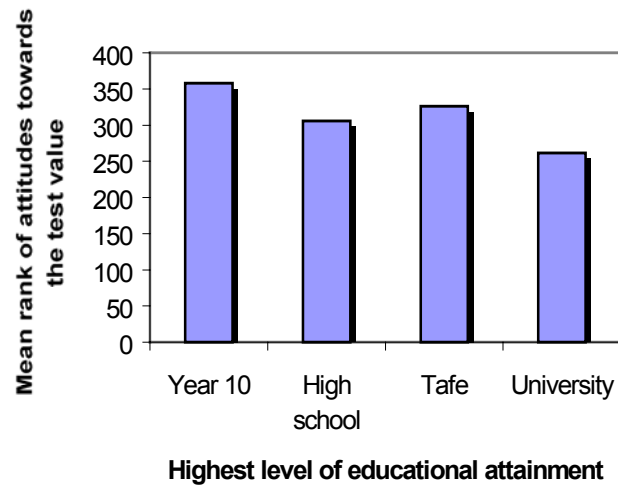


Figure 2. Mean rank attitude scores towards the value of the tests for each level of educational attainment.

## Discussion

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The aim of the present study was to determine the availability of information, specifically to Western Australian women, regarding prenatal screening and diagnostic procedures and subsequently determine their knowledge, attitudes and experiences in this area. In addition the study was designed to provide baseline statistics for the first phase of a longer-term study. The two main outcome measures were knowledge and attitudes. Three attitude factors were identified, namely attitude towards the adequacy of information, attitude towards the value of prenatal tests and confidence in results.

Specific gaps in knowledge were identified from items in the knowledge scale, which more than half of the sample answered incorrectly. The areas identified include the prevalence of birth defects, the main purpose of screening tests, what specific conditions are being screened, recall rates, false positive rates, test accuracy, and the fact that Fefol has a limited protective effect for NTD. Therefore, further efforts in education should be targeted at these areas.

As expected, knowledge was found to increase with age, however, the strength of the relationship was only small. Initially it could be explained that an increase in age correlates with a woman's experience in procedures, associated with pregnancy and antenatal care. Therefore, it would be expected that a woman's knowledge with the procedures should also increase with her experience with the procedures. The more times a woman falls pregnant, the more times she may be exposed to the procedures themselves, or information on the procedures, and thus her knowledge would be expected to increase. However, it was found that knowledge was not significantly correlated with either the number of pregnancies or the number of children and thus knowledge was not related to experience. It is possible that some women may rely on the information initially received during their first pregnancy and do not actively search for additional information. As a result knowledge may remain static across pregnancies. This is supported by the fact that 30% of women reported that they received most of their information from their previous pregnancies.

This however does not account for the finding that knowledge increases with age. An alternative explanation is that the age of the women is the important factor rather than the number of pregnancies. For example, both a 16-year-old and a 30-year-old may be experiencing their first pregnancy, however, it is the elder of the two who were found to have the higher knowledge. It could then be suggested that the older the woman, the more inclined she is to adopt information-seeking behaviours, especially considering the fact that the risk of birth defects and hereditary conditions increases with age [6]. In fact, the reasons consistently

mentioned by women for deciding not to undergo either screening or diagnostic tests, was that they “weren’t necessary” and they were “not aged above 35-37 years”. This suggests that women are aware that the risk increases for those above this age-range for having a child with a genetic disorder, thus younger women may be less inclined to actively seek additional information.

In addition, it was found that as age increases so too does the attitude towards adequacy of information and confidence in results, but again this association was not large. Therefore, it seems that the older the women, the more positive they are towards information received and the more confident they are in results. Thus, increased efforts should be made to specifically target younger women. However, due to the size of the association being small in the current sample, further research should clarify the relationship between age and knowledge and attitudes towards prenatal procedures.

Knowledge was also associated with the level of educational attainment, such that university graduates were found to have a higher level of knowledge than all other levels of education. As with age, this may also be related to information-seeking behaviours whereby those with a university education may seek more information and thus have a higher awareness and understanding of the procedures than women with other educational levels. Interestingly those women with other education levels were found to have more positive attitudes towards the value of the tests. That is, the university graduates, although with higher knowledge levels, felt more negative towards the value of the procedures.

Consistent with previous findings [4, 10], further results showed that those who did not have a screening test were found to have a higher knowledge level than those who did actually take a screening test. However, those who did not have the tests felt more negatively in terms of the value of the tests and confidence in results, as well as adequacy of information, despite their higher knowledge levels. A possible explanation is that the variable concerning women’s attitudes towards the adequacy of information consisted of items implying the level of satisfaction with information given to them by their health care provider. Due to this, women who did not undertake testing may have chosen to seek additional information elsewhere which explains why they felt negatively towards the adequacy of information despite their higher knowledge levels. This is consistent with the results of Al-Jader et al. (2000) and Santalahti et al. (1998) who found that information may also serve to dissuade women to undergo screening tests.

Although those who took the test felt positively towards the adequacy of information, they may not have fully understood it, as evident in their lower knowledge scores. As stated by one woman “I do however recall being offered lots of information, verbally and via pamphlets.

At the time I was unable to absorb a lot of it due to stress.” This suggests that this woman may have had a positive attitude towards the adequacy of information, however, due to her inability to absorb that information may not have fully understood the tests or their implications. As found by Baillie et al. (2000), the amount of information given to women in an effort to inform posed an additional burden. Women were unable to assimilate information, which made decision-making especially difficult. As a result, this study suggests that women be given more support and time to absorb the information, perhaps offered a follow-up appointment to discuss any concerns and ask any questions before they make a decision to have the tests. Evidently, it is not the perception of the availability of information that is the important factor, but rather the understanding of that information.

Those with private health coverage and those who reported having seen information pamphlets, were found to have higher knowledge and a more positive attitude towards adequacy of information and confidence in results, but not towards the value of the test. Similarly, those in the metropolitan area, as opposed to those in the rural area, had higher knowledge and a more positive attitude towards adequacy of information only. This may suggest that private patients and metropolitan residents have a greater access to information on prenatal tests. As a result, public patients and those living in, or accessing services in rural areas, are identified as groups of women requiring additional support. However, in relation to the statement that pamphlets had been sighted, only one produced by the Department of Health was available at the time, which addressed MSS. More pamphlets, however, were released during the month that the present sample gave birth. It is unlikely that the pamphlet believed to be sighted was that produced by the Department of Health, however it is encouraging that women are seeing some information and that it seems that this information is having an impact on their knowledge level and attitudes towards the adequacy of information.

In relation to women’s experiences with the procedures, women identified the top three reasons for choosing to undertake screening tests as “to ensure the baby was healthy”, “to see the baby” and that it was perceived as being a “routine” test. This is consistent with former studies [6, 10, 12], which found that one of the main reasons women undertake these tests is because they believe they are routine and generally reassure themselves that the baby is all right, rather than to test for a specific genetic disorder. In further support of Baillie et al. (2000) and Press and Browner (1997), it appears that women’s knowledge of the actual procedure (production of a picture to see the fetus), is higher than their knowledge of the purpose of the procedure (screening for fetal anomalies). That is, it is perceived to be more of a social rather than medical event.

Reasons cited for undertaking the diagnostic tests included the need “to make sure the baby was healthy”, but importantly it was cited as “the care provider’s decision” and to be “conforming with the care provider’s suggestion”. As reported by French et al. (1992), some care providers are directive in their health care manner and women may view that the care provider knows what is best for them. This is evident in some of the comments made by women:

“I was feeling quite pressured to have the tests before I took them - I knew I wanted to do something and that it was my choice, but still I felt pressured. The impression given by my Gynecologist/Obstetrician was that he knew what was best and therefore gave little to no explanation of MSS other than I should have it”

“My Obstetrician was not very accepting of my decision to have no screening or diagnostic tests - he described me as slipping through the system”

“None of the tests were explained properly, only the Down syndrome test, and no test results or why the tests were being done was explained. I only got told “You have a nice healthy baby in there”. Other stuff mentioned was in medical terms. I just figured if something was wrong the doctor would tell me”

“I was told to have a blood test but was never told why or what the results were”

“I’m unsure as I can’t remember what tests I had when I was pregnant. I still have baby brain (mushy brain). My GP was very good though and I trusted his judgement”

Each of these comments illustrate the faith that women hold in their health care provider to make the decision on their behalf. In contradiction to the previous points regarding an abundance of information and an inability to absorb it, these comments suggest that adequate information and explanations were not provided. It seems necessary to emphasise the point that women need information and support, time to assimilate the information and time to discuss it further.

Overall there were mixed feelings among women specifically pertaining to their experiences with their health care provider, as the following comments demonstrate:

“Anecdotal stories abound regarding the lack of sensitivity and compassion that health care workers demonstrate when giving tests and information to pregnant women. I feel sure that much of testing is unnecessary and this is seldom explained with clarity and patience”.

“I booked into my Obstetrician when I was only seven weeks pregnant but the receptionist wouldn’t give me an appointment before 13.5 weeks which would have been too late for first trimester testing. Luckily I knew about it through my work and organised it all through my GP (who knew nothing about it). When I tried to push the receptionist regarding this she told me to

"just see your GP". This was obviously not good enough. All pregnant women should have all choices, I believe. Naturally I received no counselling."

"I found the hospital to be complacent about procedures as I was not informed of the transnuchal scan until it was too late and when I asked the hospital this they told me they could not offer the test due to lack of funding which I found to be absolutely absurd."

"I feel very lucky that WA has such a thorough health care system. I found that if you ask, there are many options and support given regarding MSS."

"I was very happy with my doctor and the tests I had done during my pregnancy which put my mind to rest worrying if my baby was OK."

"The care given to me by medical staff was excellent."

It then seems that a vital area of further investigation lies in the services and information offered by health care providers. Bearing these in mind, efforts may be made to improve the services provided.

The reasons cited for deciding not to undertake prenatal procedures vary across tests. For example, although the miscarriage risk is higher for CVS in comparison to amniocentesis, this risk was only cited as a reason against undertaking amniocentesis. Further to this, 37%, as opposed to 5%, of women selected "not knowing about the tests" as a reason for choosing not to undertake CVS and amniocentesis respectively. This was also cited as a major reason for choosing not to undertake MSS. This suggests that women are more familiar with the amniocentesis procedure and thus it appears that MSS and CVS are areas to target in future education for women.

In the case of ultrasound, 29% stated they "did not want to be faced with an unwanted decision". The comments consistently revealed that women would not undergo procedures as they would not "do anything about it anyway" should they discover their unborn child had a genetic disorder. This supports Browner et al. (1996) who found that women may pass up screening and invasive diagnostic procedures to avoid being faced with an unwanted decision regarding the fate of their unborn baby. This demonstrates that women may not be aware that there are reasons for prenatal testing other than for the termination of an affected fetus. As one woman commented:

"What many fail to realise is that, for example, if their baby had a heart defect detected before birth the appropriate form of delivery and on the spot care can be initiated before things get out of hand and an emergency situation arises. If their baby is determined to have Down syndrome, they can be guided towards the right support group(s) if they continue the pregnancy."

As further commented by Yankowitz, Howser, and Ely (1996), many advantages have been identified for prenatal tests including the alleviation of worry for many couples and emotional, physical and financial preparation for birth, of which all women should be informed.

While taking into consideration the present results, it must be acknowledged that the correlations reported were small and must be viewed tentatively. It should also be noted that this was a retrospective self-report survey. One concern of the present study was women's recall in regard to the procedures they undertook. Despite every effort being made to reduce the impact of time, while still allowing women a break following the birth of their child, some comments indicated that women just could not remember which tests they had. Ideally, women could be approached in the first half of their pregnancy to allow for this. Future research, however, could focus on following women from the time they are pregnant and having these tests, to six months after their pregnancy to determine how well women recall their experiences at this time and what impact this has on future pregnancies and decisions.

Due to the confidential nature of the study, women were not required to include their names. As a result, individual demographic details could not be obtained on the non-respondents; however, general percentages were obtained at pre-test and on the returned sample. It appeared that the sample was slightly over-represented by those women who held a higher education and who were private patients. It may be that these groups of women felt more confident in their knowledge or experiences and thus were more inclined to participate.

The study was limited by not including those women who were of non-English speaking backgrounds. The cost to translate and back-translate the survey into other languages was too expensive and so women who spoke other languages were excluded from the study. Although those who speak languages other than English often have different cultural backgrounds, the ethnicity reported by the present sample widely varied and thus these cultural views may not necessarily have been excluded. The impact of cultural beliefs and ethnicity could be evaluated further in future research addressing the availability and need for multicultural prenatal services and the difficulties currently experienced in this area by women from multicultural backgrounds.

Some major areas have been identified for further attention with regards to educational efforts. Particular groups of women were identified as requiring added support and education including younger women, women in rural areas and women utilising the public health system in Western Australia. Furthermore, those with a lower educational attainment were found to have lower knowledge levels; thus we conclude that education on prenatal tests should begin in year 10 before women begin to leave school. Extra efforts should be made to ensure that those women who are choosing to have the test understand the information they have been provided

with and are actually actively making the decision themselves and have not been influenced by their health care provider. Additional research should be directed towards the knowledge and service provision of health care providers to determine how the tests are being introduced and to what extent pre- and post-test counselling is being provided.

This study highlights the fact that attention should be focussed on particular areas of prenatal testing. Areas identified included educating women more thoroughly on the purpose of the tests, focussing on which conditions the screening tests detect in addition to the procedure itself. Further information should be available on the recall rates and false positive rates of the tests and explanations as to what these indicate. The fact that the tests are voluntary should be emphasised and that the results may also be used in preparation for the birth of an affected fetus rather than solely in the choice to terminate. A greater focus should be directed towards the education of women in the availability, procedure, and risks involved with CVS and MSS.

Further research should also be conducted into women's understanding and interpretation of their own results. How these results are communicated (face to face or over the telephone), the form in which it is recommended (individual risk or increased risk), and how women interpret them. Furthermore, the outcome of the pregnancy or the results of the tests were not of interest in the present study, however these factors may impact on a woman's view and experience with the tests and thus could be explored in future research.

## **Summary**

### **Conclusions for service delivery:**

- **Education should focus on the purpose of tests, prevalence of birth defects, the conditions themselves, CVS and MSS, recall rates and false positive rates of the tests, test accuracy and the fact that the tests are voluntary and results can be used for the preparation of birth.**
- **Groups of women to be targeted include younger women (high-school age), women without private health coverage and women in rural areas.**
- **Women need to be provided with more support, time to assimilate information and should be offered a follow-up appointment.**

### **Directions for future research:**

- **Clarification of the relationship between age and knowledge and attitudes towards prenatal procedures.**
- **Investigation of knowledge and services provided by health professionals and the extent to which pre- and post-test counselling is offered.**
- **Women's recall of their experiences and how these impact on future pregnancies and decisions.**
- **Women's understanding and interpretation of their own results.**
- **How the outcome of a test result and the pregnancy impacts on women's attitudes and experiences.**

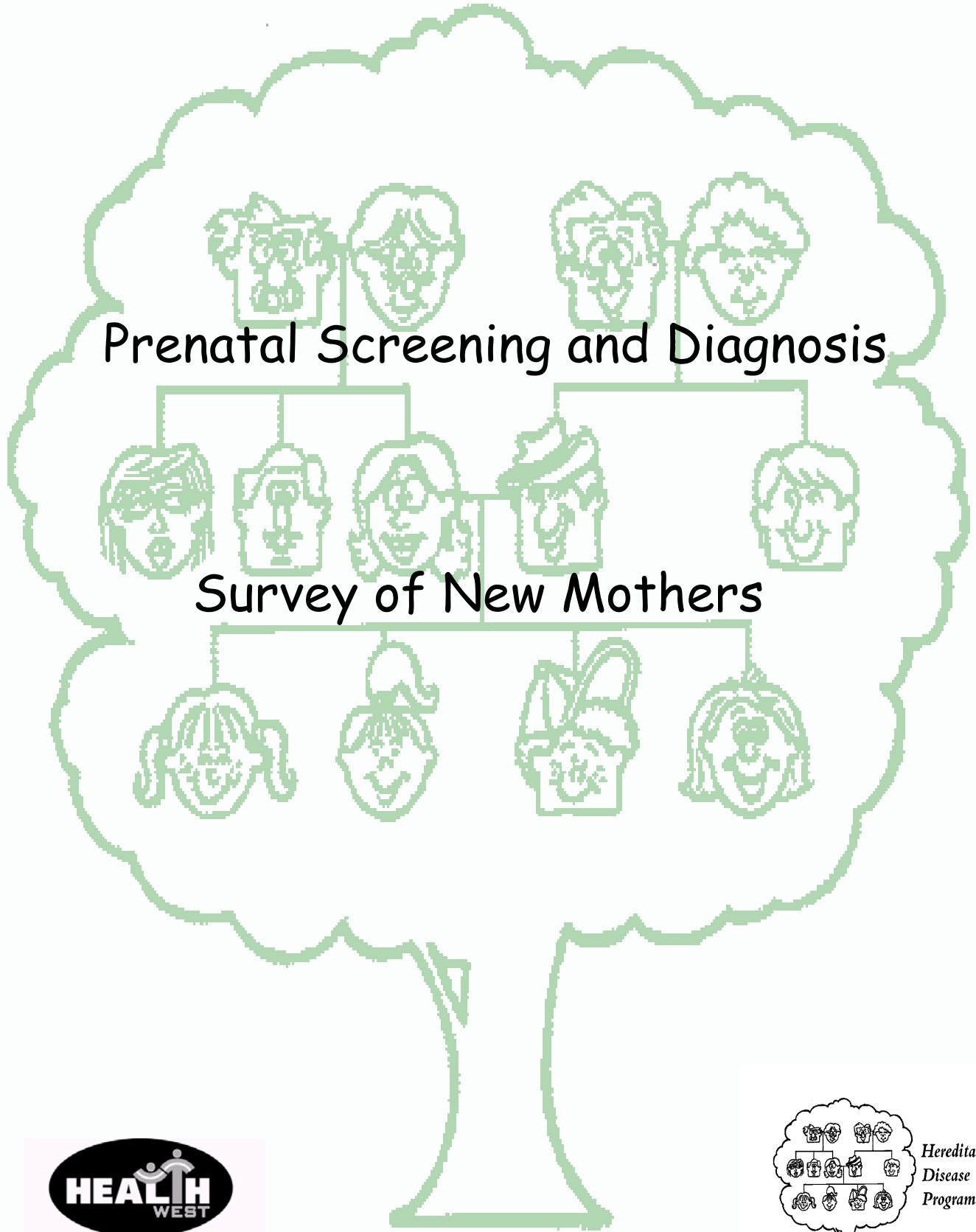
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Appendix I

Hereditary Disease Program  
Department of Health

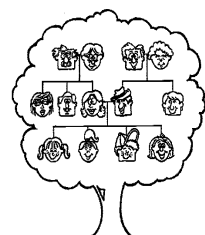


Prenatal Screening and Diagnosis

Survey of New Mothers



DEPARTMENT OF HEALTH



Hereditary  
Disease  
Program

October 2001

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

**1. Have you heard of ANY of these prenatal tests?**

Yes  ⇒ Please continue

No  ⇒ Please go to Question 53 on page 8

**EXPERIENCE**

In this section we are interested in your experiences with fetal prenatal screening and diagnostic procedures.

**2. (Please tick either the "Yes", "No" or "Unsure" box for each part of the question):**

**Which of the following tests have you:**

	Heard of	Been given a choice to have	Understood reasons for having	Actually had
<b>Ultrasound and blood test before 11-13 weeks / approximately 3 months of pregnancy (for Down syndrome)</b>	Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>
<b>Second trimester maternal serum screening (MSS) (for Down syndrome and neural tube defects)</b>	Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>
<b>Amniocentesis</b>	Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>
<b>Chorionic villus sampling (CVS)</b>	Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/>

3. Below are some possible reasons why women have prenatal screening and diagnostic tests. For each of the tests that you have ACTUALLY HAD please tick each of the reasons that may apply to you.

If you DID NOT have ANY of these tests please go to Question 4 on page 3.

Reasons	Screening and Diagnostic Tests			
	Ultrasound and blood test before 11-13 weeks / approximately 3 months of pregnancy	Second trimester maternal serum screening	Amniocentesis	Chorionic villus sampling
You wanted to see the baby				
It's just a routine thing that's done when you're pregnant				
You wanted to make sure the baby was healthy				
You are aged 35 to 37 years or older				
You have had more than two miscarriages				
You let the care provider decide on the tests for you				
Conformity with the care provider's suggestion				
You were concerned about the risk of birth defects and/or hereditary conditions				
You, your partner or another family member has a hereditary condition that you were concerned might be passed onto your children				
Wishing to take any medical tests offered				
You and your partner are closely related				
Other (Please write your answer in the relevant square)				

4. Below are some possible reasons why women prefer NOT to have prenatal screening and diagnostic tests. For each of the tests that you DID NOT HAVE please tick each of the reasons that may apply to you.

Reasons	Screening and Diagnostic Tests			
	Ultrasound and blood test before 11-13 weeks / approximately 3 months of pregnancy	Second trimester maternal serum screening	Amniocentesis	Chorionic villus sampling
It wasn't necessary				
You didn't know about them				
They weren't available				
You did not want to be faced with an unwanted decision				
They're not accurate				
The risk was too high				
You were not concerned about the risk of birth defects and/or hereditary conditions				
You are not aged 35 to 37 years or older				
Other (Please write your answer in the relevant square)				

5. Have you seen the Department of Health's pamphlets regarding hereditary diseases and prenatal screening? *(Please tick ONE box ONLY)*

Yes

No

Unsure

6. Where did you first find out about the tests? *(Please tick ONE box ONLY)*

GP  Pamphlets/resources

Specialist  Internet

Media  Previous pregnancies

Family  Other (Please specify)

Friends  \_\_\_\_\_

Clinic  \_\_\_\_\_

7. **How were you first introduced to the screening test (ultrasound and blood test)? (Please tick ONE box ONLY)**

- |  |                          |  |                          |
|--|--------------------------|--|--------------------------|
| As a test recommended in pregnancy                     | <input type="checkbox"/> | I did not understand the reason for the test | <input type="checkbox"/> |
| As an obligatory test in pregnancy                     | <input type="checkbox"/> | Other (Please explain)                       | <input type="checkbox"/> |
| As a precaution because I was <i>at increased risk</i> | <input type="checkbox"/> | _____  | _____                    |

8. **Who / what provided you with the most information during the first half of your pregnancy? (Please rate your top 3)**

- |            |                          |                        |                          |
|------------|--------------------------|------------------------|--------------------------|
| GP         | <input type="checkbox"/> | Pamphlets/resources    | <input type="checkbox"/> |
| Specialist | <input type="checkbox"/> | Internet               | <input type="checkbox"/> |
| Media      | <input type="checkbox"/> | Previous pregnancies   | <input type="checkbox"/> |
| Family     | <input type="checkbox"/> | Other (Please specify) | <input type="checkbox"/> |
| Friends    | <input type="checkbox"/> | _____                  |                          |
| Clinic     | <input type="checkbox"/> | _____                  |                          |

**ATTITUDES**

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

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
<i>Example</i> Summer is the best time of year	1	2	3	4	5
<b>Your Answer(s)</b>					
9. Prenatal screening tests are valuable.	1	2	3	4	5
10. Prenatal screening tests benefit all pregnant women.	1	2	3	4	5
11. All pregnant women should have prenatal screening tests.	1	2	3	4	5

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neither Agree nor Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
12. The cost of prenatal screening tests should not influence whether they are done or not.	1	2	3	4	5
13. If I were to have another pregnancy I would have prenatal screening tests.	1	2	3	4	5
14. During my pregnancy I was worried about my baby's health.	1	2	3	4	5
15. Prenatal screening tests help reduce anxiety during pregnancy.	1	2	3	4	5
16. It would be very difficult for me if I had a child with a serious abnormality.	1	2	3	4	5
17. During my pregnancy I was certain that my baby was healthy.	1	2	3	4	5
18. The information I was given made me worry about my baby.	1	2	3	4	5
19. I had enough time to make a decision whether or not to have the test.	1	2	3	4	5
20. I was provided with enough information about prenatal screening tests.	1	2	3	4	5
21. The information I was given was clear.	1	2	3	4	5
22. My doctor/midwife knew enough about the tests that were available.	1	2	3	4	5
23. I was given enough information to help me make the decision to have the test.	1	2	3	4	5
24. The results of my tests were explained clearly.	1	2	3	4	5
25. I felt confident about the results of my tests.	1	2	3	4	5
26. I was given enough information about the test results.	1	2	3	4	5

### 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.** For each statement please indicate with a tick whether it is your opinion that the statement is “true”, “false” or you’re “unsure”.

	True	False	Unsure
27. A birth defect occurs in 5% (1 in 20) of all pregnancies.			
28. An ultrasound can be used to detect every kind of birth defect.			
29. The main use of an ultrasound is to check the age and growth of the baby.			
30. Following a screening test, 5% (1 in 20) of women receive an <i>at increased risk</i> result.			
31. Most women (98%) who receive an <i>at increased risk</i> result have healthy babies.			
32. Tests can be done as early as 11-13 weeks / approximately 3 months to identify pregnancies at risk of Down syndrome.			
33. First trimester screening involves ultrasound and a maternal blood test.			
34. If a first trimester screening test shows <i>at increased risk</i> , further tests can be done to clarify a diagnosis.			
35. Second trimester maternal serum screening detects only Down syndrome.			
36. Second trimester maternal serum screening is routine for all pregnant women.			
37. If second trimester maternal serum screening shows <i>at increased risk</i> , further tests can be done to clarify a diagnosis.			
38. Women who have normal second trimester maternal serum screening can be certain that they will have a healthy baby.			
39. Prenatal screening tests pick up 100% of abnormalities.			
40. If a positive or <i>at increased risk</i> result is given this means the fetus definitely has Down syndrome or a neural tube defect.			
41. Amniocentesis is a test of the mother’s blood.			
42. Amniocentesis is a test that detects only Down syndrome.			

	<b>True</b>	<b>False</b>	<b>Unsure</b>
43. Amniocentesis is routinely offered to women aged 35 to 37 years or older.			
44. All hereditary conditions can be detected before birth.			
45. Folic acid is important in preventing 70% of neural tube defects.			
46. A neural tube defect is when something is wrong with the baby's brain or spinal cord.			
47. The best time to start taking folic acid is as soon as your pregnancy is confirmed.			
48. Multivitamin supplements always provide enough folic acid.			
49. Fefol contains enough folic acid to give a protective effect for neural tube defects.			
50. A negative result from a chorionic villus sampling guarantees the absence of all birth defects and/or hereditary conditions.			
51. There is a chance of miscarriage associated with chorionic villus sampling and amniocentesis.			
52. The results of chorionic villus sampling are 99% accurate.			

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

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## BACKGROUND INFORMATION

The following questions ask for background information about yourself.

55. What is your year of birth? \_\_\_\_\_

56. What is your postcode? \_\_\_\_\_

57. What is the highest level of education you have completed? (*Please tick ONE box ONLY*)

- |   |                          |  |                          |
|---|--------------------------|--|--------------------------|
| Completed Year 10                         | <input type="checkbox"/> | University, CAE, or some other tertiary institute degree | <input type="checkbox"/> |
| Completed high school (i.e. Year 12, HSC) | <input type="checkbox"/> | Other (please specify)                                   | <input type="checkbox"/> |
| TAFE or Trade Certificate or Diploma      | <input type="checkbox"/> | _____  | _____                    |

58. To which ethnic group do you belong? \_\_\_\_\_

59. Do you have private health coverage? (*Please tick ONE box ONLY*)

Yes

No

60. How many pregnancies have you had? \_\_\_\_\_

61. How many children do you have? \_\_\_\_\_

Should you wish to (*Please tick*):

Participate in a further interview regarding your experiences

Receive further information on prenatal screening and diagnosis

Please fill in the details below and we will contact you at a future date; if not please leave the following details blank.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone number(s): \_\_\_\_\_ (Hm) \_\_\_\_\_ (Wk)

\_\_\_\_\_ (Mob)

## Appendix II

### Members of the Reference Group

Dr. Caroline Bower	Birth Defects Department King Edward Memorial Hospital
Vivien Gee	Maternal and Child Health Unit Department of Health
Dr. Barry Lewis	Head of Department Clinical Biochemist Princess Margaret Hospital
Dr. Jann Marshall	Public Health Senior Coordinator

## Appendix III

### **Participant's Covering Letter**

**To the new mum,**

You have been randomly selected from all women who gave birth during the month of July 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 to raise awareness of hereditary conditions and birth defects. As a result, the program is conducting the present survey about women's knowledge, attitudes and experiences with prenatal screening and diagnostic procedures.

By returning the **enclosed** survey you will be providing valuable information that will help the Hereditary Disease Program determine how our services for pregnant women can be improved. Consequently, the information provided will not only prove beneficial to other pregnant women in the future, but also possibly to you.

The survey is completely voluntary and confidential. This means that you may withdraw from the study at **any** time. Your responses will remain anonymous, as there is **no** identifying information on the survey. However, a section has been included at the end to provide you with the option of including your contact details should you require any further information or should you wish to take part in a further interview. Please note that on receiving your completed survey this section will subsequently be removed. 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 the **26<sup>th</sup> October 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.

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



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