

Women's Experiences of Non-Invasive Prenatal Testing

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Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to this copy of my thesis, when deposited in the University Library*, being made available for loan and photocopying subject to the copyright Act 1968.

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Acknowledgement of Collaboration

I hereby certify that the work embodied in this thesis has been done in collaboration with other researchers. I have included as part of this thesis a statement clearly outlining the extent of collaboration, with whom and under what auspices. I contributed to the development of the research question, the database search, the statistical analysis, the interpretation of results and editing of the manuscript. My supervisor, Dr. Linda Campbell contributed to the development of the research question, the formulation of the methodology, the interpretation of results, and editing of the manuscript. Taylah Armstrong assisted in the project development and data collection. Dr Tracy Dudding-Byth contributed to the development of the research project and editing of the manuscript. Dr Rina Fyfe assisted in the data collection.

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Unsubmitted manuscript formatted for the Journal of Genetic Counselling

See Appendix A for submission guidelines (please note that tables and figures have been included in-text for purpose of thesis review and marking).

Women's Experiences of Non-Invasive Prenatal Screening

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Abstract

While the uptake of non-invasive prenatal testing (NIPT) continues to increase, the provision of pre-test genetic counseling remains unregulated in Australia. This study sought to characterise the experiences of women undergoing NIPT. We investigated participants' perceptions of informed choice, genetic counseling experiences and decision to undergo NIPT. Women who had been recently pregnant volunteered to complete an online survey which assessed their knowledge of and attitude toward NIPT; satisfaction with genetic counseling; satisfaction of their decision, and decisional conflict to undergo NIPT. The survey also gathered pregnancy-specific and demographic information, and allowed participants to provide qualitative information about their counseling experience and reasons for undergoing NIPT. A total of 94 participants were included in the analysis. Overall, participants had good knowledge of and positive attitudes toward NIPT, experienced low decisional conflict and were overall satisfied with their genetic counseling experience and decision to undergo NIPT. Some participants however, expressed dissatisfaction with the lack of information provided and biased language by pre-test genetic counseling providers. The desire to be informed was the most frequent reason for undergoing NIPT. This study highlighted the importance of providing accurate and objective information in pre-test genetic counseling to reduce decisional conflict and improve satisfaction with the decision to undergo NIPT.

Key Words: Genetic Counseling; Decision Making; Genetic Testing