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THE UNIVERSITY OF NEWCASTLE AUSTRALIA

Information Statement for the Research Project:
Contraceptive choice for women with chronic disease

Document Version 2; dated 31/08/20

Thank you for your continued participation in the Women's Health Australia project. We appreciate the demands on your time and your continued involvement is highly valued.

When you agreed to take part in the Women's Health Australia project, we mentioned that you might be invited to participate in projects on a range of health issues between main surveys. This is an invitation to take part in a study concerning your experiences with contraception, particularly in relation to having a chronic disease. Your responses and experiences are important and may serve to influence decisions about sexual and reproductive care for women with chronic disease.

This project is being led by Dr Melissa Harris, a Senior Research Fellow at the Research Centre for Generational Health and Ageing, University of Newcastle. This project has been funded as part of Dr Harris' Australian Research Council Discovery Early Career Researcher Award (DE190101134) which has an overarching goal of understanding contraceptive decision-making and unplanned pregnancy among women with chronic disease. This study is being conducted in collaboration with researchers from the University of Newcastle (Professor Deborah Loxton), La Trobe University (Professor Jayne Lucke), University of Melbourne (Dr Jacqueline Coombe) and Family Planning NSW (Dr Deborah Bateson).

Why is the research being done?

The purpose of the research is to explore further how women with chronic disease (and their partners) make contraceptive decisions.

Who can participate in the research?

Women who have a chronic health condition who use and don't use contraception can participate in the research. You were selected from the Women's Health Australia database because you: (1) indicated in a previous survey that you had a chronic health condition or had an indication for a chronic health condition in either the Medicare Benefits Schedule, Pharmaceutical Benefits Scheme or state-based hospital records; and (2) indicated in survey 5 that you had a male partner.

What would you be asked to do?

If you agree to take part, you will be asked to participate in a confidential telephone interview, conducted by Dr Melissa Harris. This interview will take place at a time

convenient for you. In the interview you will be asked questions about how you make contraceptive decisions, where you get your information from; and what could be improved or developed to assist women (and their partners) to make informed decisions about their fertility. The interview will be audio recorded using voice recording software and then transcribed for analysis by an administrative assistant who is bound by strict privacy protocols. Please note that during the interview you will have the right to at any time review the recording and ask for sections to be erased. You will also be given the opportunity to review, edit or erase a typed copy of the interview by contacting the researchers on the email below. Following the conclusion of the interview, you will be sent a $30 gift voucher as compensation for your time.

But what about my partner?

If you have a male partner, with your permission we would like to invite them to participate in a separate confidential interview about his role in making contraceptive decisions to gain a better understanding of how this occurs at a couple level. Please note, it is completely your choice. If you would prefer to participate on your own, you can. If your partner is interested in participating, we will ask you to forward a separate email invitation and participant information statement to him on our behalf.

What choice do you have?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you. If you do decide to participate, you may withdraw from the study at any time without giving a reason and have the option of withdrawing any data which relates to you up until the results are submitted for publication.

How much time will it take?

The telephone interview should take about 1 hour to complete.

What are the risks and benefits of participating?

We cannot promise you any direct benefit from participating in this research, however your contribution will help us better understand the sexual and reproductive needs of women with chronic health conditions. The information from these interviews will also be used to develop a contraceptive decision-making tool to assist women with chronic health conditions (and their partners). While we do not expect that there will be any problems or risks associated with participating in this study, some people may become upset when talking about their life experiences. If you become upset by any of the questions you may stop the interview or decide to take a break. You might also like to consult your local GP or contact Lifeline on 13 11 14 or the Family Planning NSW Talkline on 1300 658 886.

How will your privacy be protected?

Any information collected by the researchers which might identify you will be stored securely and only accessed by the researchers named in this document and the ALSWH staff that maintain participant records. If your partner decides to participate, he will not be aware of your responses and vice versa. Data will be retained securely for a minimum period of 5 years from completion of the research and managed/stored in accordance with the University's Research Data and Materials Management Guideline (see https://policies.newcastle.edu.au/document/view-current.php?id=72) or any successor Guideline, and applicable University of Newcastle policy provisions (as amended from time to time). Access to any identifiable data will be restricted to members of the research

team, unless you have consented otherwise; or disclosure is required by law in order for us to comply with our regulatory obligations. You will remain anonymous in any research publications or presentations that are based on the interview. Please note however, that the audio-recorded interviews will be destroyed at the conclusion of the study, following checks for accuracy. Further, to save you re-answering questions that you have already answered in previous surveys, we will link your responses from this interview to your answers from those surveys.

How will the information collected be used?

The information collected will be reported in academic papers submitted for publication in journals and presented at conferences and research meetings. The information collected will also be used to inform the development of a contraceptive tool to assist young women with chronic health conditions navigate contraceptive decision-making and reproductive planning. Individual participants will not be identified in any publications arising from the project. Non-identifiable data may also be shared with other parties to encourage scientific scrutiny, and to contribute to further research and public knowledge, or as required by law. You may request a copy of the interview transcript to edit or erase your contribution prior to the conclusion of the project or publication of results; whichever occurs first. A lay summary of results will be available to all participants upon request following completion of the project.

What do you need to do to participate?

Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, contact Dr Melissa Harris on the details below. If you would like to participate, you do not need to do anything. Melissa will call you in the next 1-2 weeks to arrange a time convenient to you to complete the interview. In the meantime, if you would like to let Melissa know your preference to participate or not, you can contact her on the details below.

Further information

If you have any questions about this study, please contact Dr Melissa Harris (Chief Investigator) by email Melissa.Harris@newcastle.edu.au or phone (02) 4042 0621. Alternatively, you may call Women's Health Australia through their usual channels including the FRECALL number 1800 068 081 and email alswh@newcastle.edu.au.

Thank you for considering this invitation.

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Complaints about this research

This project has been approved by the University's Human Research Ethics Committee, Approval No. H-3030-0226. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred,

to the Human Research Ethics Officer, Research & Innovation Services, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 4921 6333, email Human-Ethics@newcastle.edu.au.