



Participant Information Sheet

Women with diminished ovarian reserve

Project Title: *A survey of women with diminished ovarian reserve (DOR) to explore their health needs, treatment decisions and experiences*

Project Summary:

The research study is an online survey to describe the health needs and what treatments and practices are offered to women with DOR. We're especially interested in any complementary medicine that women have used to assist with DOR. There is some emerging evidence that these therapies may be helpful alongside medically assisted reproduction for fertility, and this survey will inform the direction of future research priorities.

We are interested in the health needs and experiences of all women with DOR, therefore, you do not need to have used complementary medicine to complete this survey.

You are invited to participate in a research study being conducted as part of a PhD project of Ms Alison Maunder under the supervision of Dr Carolyn Ee, Dr Mike Armour, Dr Susan Arentz at the NICM Health Research Institute at Western Sydney University. It has Ethics approval (H14256 March 2021). If this survey raises any concerns or causes you to experience any discomfort, please contact your GP, Lifeline phone 131114 or one of the following organisations that support women who have experienced infertility or miscarriage:

ACCESS Australia <https://access.org.au/>

Pink elephants <https://miscarriagesupport.org.au>

How is the study being paid for?

No external funding has been sourced for this study. Ms Maunder's position as a PhD candidate is supported by a scholarship from the Jacka Foundation of Natural Therapies.

What will I be asked to do?

You will be asked to complete an anonymous, online survey that will ask you about

- details of your DOR diagnosis, treatment provided and some brief medical details
- use of complementary therapies, including naturopathy that you have used in general and specifically for DOR
- lifestyle habits such as smoking, alcohol intake and physical activity
- a future trial design of a treatment option for DOR
- demographics

How much of my time will I need to give?

We have piloted the survey with women with DOR and have found that it takes between 20-30 minutes.

What benefits will I, and/or the broader community, receive for participating?

Although you will not receive any direct benefit from participating, your responses will inform researchers about:

- the health needs and treatment patterns of women with DOR
- perceived effectiveness of different interventions
- the potential role of complementary therapies as additional treatments that may help with DOR

This new information, which has not been collected in Australia as far as we know, will inform the direction of future research priorities so that potential treatments can be trialled in the care of women with DOR.

Will the study involve any risk or discomfort for me? If so, what will be done to rectify it?

You will be giving up some of your time to complete this survey. Some women may find it distressing to answer questions about the diagnosis of DOR and fertility. However, we have worked closely with consumer representatives (women with DOR) to ensure these questions are asked sensitively.

How do you intend to publish or disseminate the results?

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that the participant cannot be identified. As the survey is collected anonymously, your responses will not be able to identify you at all.

Will the data and information that I have provided be disposed of?

No. Your data will remain with the investigators of this research.

Can I withdraw from the study?

Participation is entirely voluntary and you are not obliged to be involved. If you do start the survey, you can stop at any time and exit the survey without completing it. Submitting your completed questionnaire is an indication of your consent to participate in the study. Once you have submitted the survey, we will not be able to remove your data as it will be anonymous.

Can I tell other people about the study?

Yes, you can tell other people about the study by forwarding the link to the online survey.

What will happen with my information if I agree to it being used in projects other than this one?

Thank you for considering being a participant in a University research project. The researchers are asking that you agree to supply your information (data) for use in this project and to also agree to allow the data to potentially be used in future research projects.

This request is in line with current University and government policy that encourages the re-use of data once it has been collected. Collecting information for research can be an inconvenience or burden for participants and has significant costs associated with it. Sharing your data with other researchers gives potential for others to reflect on the data and its findings, to re-use it with new insight, and increase understanding in this research area.

You have been asked to agree to extended consent.

Extended consent

When you agree to extended consent it means that you agree that your data, as part of a larger dataset (the information collected for this project) can be re-used in projects that are

- an extension of this project
- closely related to this project
- in the same general area of this research.

The researchers will allow this data to be used by other researchers who wish to conduct research on naturopathy, infertility and/or diminished ovarian reserve

To enable this re-use, your data will be held at the University in its data repository and managed under a Data Management Plan. The stored data available for re-use will not have information in it that makes you identifiable. The re-use of the data will only be allowed after an ethics committee has agreed that the new use of the data meets the requirements of ethics review.

The researchers want to keep the data for a significant period of time (in excess of 15 years) for possible re-use – until it is felt that it is no longer needed for research. After this time the data will be securely destroyed.

You are welcome to discuss these issues further with the researchers before deciding if you agree. You can also find more information about the re-use of data in research in the [National Statement on Ethical Conduct in Human Research](#) – see Sections 2.2.14 - 2.2.18.

<https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018>

What if I require further information?

Please contact *Alison Maunder* should you wish to discuss the research further before deciding whether or not to participate via email address: (a.maunder2@westernsydney.edu.au) or phone 0417800355

What if I have a complaint?

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through Research Integrity and Ethics on Tel +61 2 4736 0229 or email humanethics@westernsydney.edu.au.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is H14256.