



Participant Information Sheet

Project Title: *Polycystic Ovary Syndrome (PCOS) in ethnic Indian women: a global survey*

Project Summary:

You are invited to participate in a research study. The research is an anonymous online survey seeking to gather information about your experiences of PCOS diagnosis and treatment, including the use of traditional Indian medicines- Ayurvedic medicines and yoga.

This project is conducted by Ms Vibhuti Rao, PhD candidate, at NICM Health Research Institute (NICM HRI), Western Sydney University. She is supervised by Dr Carolyn Ee, Dr Mike Armour, Dr Bobby Cheema, Professor Caroline Smith, and Dr Michael de Manincor, from NICM HRI at Western Sydney University. The project has collaborated with Dr Siew Lim, (Monash University, Melbourne), Associate Professor Lisa Moran, (Monash University, Melbourne) and Dr Sabrina Gupta (La Trobe University, Melbourne).

PCOS is a heterogeneous disorder known for its complexity which affects metabolic, endocrine, and cardiovascular systems and has life-long health implications. Additionally, women's quality of life and self-image is negatively compromised due to the symptoms of PCOS. PCOS is a rapidly growing concern among ethnic Indian women. Yet, little is known about ethnic Indian women who have PCOS and are living in Australia and worldwide. What we know from recent studies is that metabolic issues such as obesity, Insulin resistance, and diabetes type 2 resulting in cardiovascular problems are increasing rapidly among ethnic Asian Indians irrespective of their geographic location. Ethnic Indian women may be more likely to use their traditional medicines, Ayurveda, and yoga to manage health issues. It is therefore important to understand the experiences of ethnic Indian women with PCOS and to explore their health needs.

Findings from this survey will help to understand the health needs of ethnic Indian women with PCOS and to inform the provision of culturally appropriate care particularly for lifestyle treatments.

How is the study being paid for?

There is no funding for this project.

What will I be asked to do?

You will be asked to complete an anonymous online survey containing questions regarding your PCOS diagnosis, treatment, diet and physical activity, and your experience with and preferences regarding the use of Ayurvedic medicines and yoga to manage symptoms of PCOS.

How much of my time will I need to give?

It is anticipated that it will take no longer than 10-30 minutes of your time.

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

There are no immediate or direct benefits to you for participating. We are conducting this research because PCOS is common among ethnic Indian women, which may impact their quality of life and has

additional challenges due to the cultural stigma associate with weight and fertility. Ethnic Indian women may tend to use their native medicines such as Ayurveda and yoga to manage their symptoms of PCOS. It is, therefore, important to understand the experiences of PCOS, diagnosis and treatment and use of Ayurvedic medicines and yoga to inform culturally appropriate care.

Furthermore, participation in this research will provide important information which will help us design an Ayurvedic diet and yoga protocol, which the research team intends to test in a future pilot study as a part of this PhD and which may help improve some of the symptoms of PCOS. Therefore, there are potential benefits to the broader community as a result of your participation in terms of improving the care that is provided to women with PCOS who are of Indian ethnicity.

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

We do not foresee any risks from participation in this study but please let us know if you have any concerns or contact your healthcare team. The helpline numbers for different countries have been given at the end of the survey for your quick access.

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, the information will be provided in such a way that the participant cannot be identified. The survey is anonymous so no identifying data will be collected. As such, you will not be identified in any publications arising from the research.

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

Please be assured that only the researchers will have access to the raw data you provide. However, your data may be used in other related projects for an extended period of time. We only intend to use the data collected from this survey to help inform an Ayurvedic diet and yoga for PCOS trial that we plan to conduct in the future as a part of the PhD.

Can I withdraw from the study?

Participation is entirely voluntary and you are not obliged to be involved. If you do participate you can withdraw at any time without giving a reason. However, as the survey is anonymous, it may not be possible to remove your data.

Can I tell other people about the study? *[Remove if not relevant]*

Yes, you can tell other people about the study by them the details of the Chief investigator Vibhuti Rao, to discuss their participation in the research project and obtain a copy of the information sheet. Alternatively, you may provide them with the survey link: <https://bit.ly/3ncdqYB>.

What if I require further information?

Please contact Ms Vibhuti Rao should you wish to discuss the research further before deciding whether or not to participate.

Ms Vibhuti Rao
NICM HRI Researcher and PhD candidate
email: v.rao@westernsydney.edu.au

Dr Carolyn Ee
PhD supervisor
Email: c.ee@westernsydney.edu.au

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 Engagement, Development and Innovation (REDI) 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.

The information sheet is for you to keep. The consent is implied when you start the survey.

This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is H14103.