

Impact of Endometriosis on Women's Lives

Do you have Endometriosis?

If Yes,

We are inviting you to complete an online Endometriosis Impact Questionnaire (EIQ).

Your valuable participation will contribute towards a better understanding of the impact of endometriosis and **to better meet the needs** of women with this condition.

Your responses are **anonymous and confidential**.

This questionnaire takes 15-30 minutes to complete online:

<https://apollo.anu.edu.au/default.asp?pid=7700>

If you have any questions about the study, or if you prefer to complete a paper copy of this questionnaire, please contact Maryam Moradi, PhD candidate, ANU.

Email: maryam.moradi.fu@gmail.com Phone: 0430 679 650

Any concerns may be directed to the Human Research Ethics Committees of ACT Health Phone: 6205 0846, or ANU Phone: 6125 3427

We appreciate your contribution to this important study.





Participant Information Form

What is the aim of this study?

This study aims to develop a questionnaire to measure the long term impact of endometriosis on different aspects of women's lives. The questions in the Endometriosis Impact Questionnaire (EIQ) have been developed based on 10 focus group discussions with 35 women with endometriosis. Your participation is valuable and will make a contribution towards better understanding the impact of endometriosis on women's lives. In turn, this will enable the needs of women with endometriosis to be better addressed.

Who is doing this study?

Researchers from the Australian National University (ANU) and Canberra Endometriosis Centre are conducting this study. Ms Maryam Moradi (PhD candidate) is the Principle Investigator under the supervision of Professor David Ellwood from the ANU. The research team also includes Professor Violeta Lopez, (ANU), Associate Professor Anne Sneddon, (Griffith University), and Ms Melissa Parker, Coordinator and Researcher at the Canberra Endometriosis Centre.

Why am I being asked to complete the Endometriosis Impact Questionnaire?

We are inviting you to complete the EIQ because you have been diagnosed with endometriosis and we are interested in your feelings and experiences of living with this condition. Completing this questionnaire is voluntary. By completing the questionnaire you are indicating your consent to participate in the study.

What will happen to my personal information if I take part?

Please be assured that all responses are confidential and anonymous and cannot be traced to a respondent. Only combined data from all the questionnaires will be reported. This study has been approved by the Human Research Ethics Committees of the Australian National University and ACT Health.

What do I have to do if I take part?

To take part, go online through the link provided and complete the: EIQ (Endometriosis Impact Questionnaire); some questions about your age and health history; and another short questionnaire (the EHP5) to compare the EIQ against other tools. This usually takes between 15-30 minutes. Simply click on the link below, or cut and paste the entire URL into your browser to access the questionnaire. **Please note the questionnaire needs to be completed in one sitting and saved by pressing "submit" on the last page.**

Link: <https://apollo.anu.edu.au/default.asp?pid=7700>

Who do I contact if I have any questions?

If you have any questions about the study or if you prefer to complete a paper copy of the EIQ, please contact Maryam Moradi PhD candidate, ANU, by email: maryam.moradi.fu@gmail.com or phone: 0430 679 650. If you have any problems with, or queries about the way in which this study has been carried out and you do not feel comfortable communicating with the researchers conducting the study, please contact the ACT Health Human Research Ethics Committee Secretariat, Canberra Hospital, Yamba Drive, Garran ACT 2605 (Ph: 6205 0846) or Human Research Ethics Committee of ANU (Ph: 6125 3427).

We appreciate your contribution to this important study.