

Consent Form - Adult providing own consent

Title National Endometriosis Clinical and Scientific Trials (NECST) Registry and Biobank

Short Title NECST Registry and Biobank

Protocol Number 62508

Project Sponsor University of New South Wales

**Coordinating Principal Investigator/
Principal Investigator** Professor Jason Abbott

Associate Investigator(s) Prof Grant Montgomery, Prof Gita Mishra, Prof Peter Rogers, A/Prof Anusch Yazdani, Dr Danny Chou, Dr Supuni Kapurubandara, Prof Luk Rombauts, A/Prof Jim Tsaltas, Dr Martin Ritossa, Prof Louise Hull, A/Prof Krish Karthigasu

Location

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as per my indicative consent of each component below and understand that the information collected will be stored indefinitely, unless otherwise notified, and that I am free to withdraw from any or all of these components of participation in the Registry at any time without affecting my future health care.

I understand that I will be given a signed copy of this document to keep.

I consent to participating by completing baseline survey data collection and having these data recorded securely in the Registry, so it is available for future related research use. I understand these data may be analysed and reported in de-identified statistical reports or approved research studies using data released from the Registry. Yes No

I consent to the collection of tissue/fluid and blood/urine samples (if available) and their use in future research in Australia and overseas. Yes No

I consent to my clinician uploading details of my medical care and treatment to the Registry, so it is available for future related research use. I understand these data may be analysed and reported in de-identified statistical reports or approved research studies using data released from the Registry. Yes No

I consent to receiving regular contact from the Registry and requests to complete further survey data collection and having these data recorded securely in the Registry. I understand these data may be analysed and reported in de-identified statistical reports or approved research studies using data released from the Registry. Yes No

I consent to my clinician providing details of any clinical specimens taken from me for biobanking, previously or in future, to the Registry, to enable researchers to invite me to participate in future approved endometriosis research projects where my specimen (if available) may be of use. Yes No

I consent to the Registry providing my contact details securely and confidentially to approved researchers for the purpose of inviting me to participate in endometriosis related research studies, including future ethically and scientifically Yes No

approved data linkage studies.

If yes, my preferred means of contact is email or phone or mail

I consent to the Registry contacting Services Australia to access my Medicare Yes No
and/or PBS claims history.

*Note: Please complete the additional Services Australia Participant Consent form

Name of Participant (please print) _____

Signature _____ Date _____

Declaration by Study Doctor/Senior Researcher†

I have given a verbal explanation of the research project, its procedures and risks, the participant has had the opportunity to contact me with questions and I believe that the participant has understood that explanation.

Name of Study Doctor/
Senior Researcher† (please print) _____

Signature _____ Date _____

† A senior member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.