

## EXPLANATORY STATEMENT

### (People with endometriosis or chronic pelvic pain Co-design Workshop)

**Project ID:** 40308

**Project title:** Endometriosis Management Plan (Endo-MP)

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You are invited to participate in a co-design workshop as part of Phase 1: Consultation and Scoping in the Endometriosis Management Plan (Endo-MP) project. The research team will seek your input into current endometriosis management in primary care and your views on how an endometriosis management plan could be successfully implemented in Australian primary care to improve endometriosis diagnosis and management. For clinicians and the community, this research aims to reduce the delay between symptom onset and diagnosis, streamline referrals and transition between services, increase awareness of endometriosis's impact, and increase service delivery efficiency.

The research is conducted through the SPHERE Centre of Research Excellence, Department of General Practice at Monash University. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information, please contact a research team member via the contact information above or email: [endo-mp@monash.edu](mailto:endo-mp@monash.edu) or phone (03) 9902 4582.

### What does the research involve?

The co-design workshop will be based on the Experience Based Co-design Toolkit. Using insights from the scoping review, literature review, general practitioner and stakeholder qualitative interviews, consumer focus groups (MUHREC ID: 37445), and the quantitative Medicine Insight data analysis (via our Associate Investigator), the Endo-MP team is developing the materials to be presented and discussed in the co-design workshop.

The workshop will include GPs, health professionals, consumers (people with endometriosis or chronic pelvic pain (CPP)), and key stakeholder groups to determine the key elements of developing and implementing an Endometriosis Management Plan (EMP) to support the navigation and management of endometriosis and chronic pelvic pain for providers and patients. Through small group activities, the study aims to collate GPs, consumers and key stakeholders' ideas for (i) optimisation of timely endometriosis diagnosis and management in primary care and (ii) implementation of an endometriosis management plan with a high degree of utility for Australian primary care, to improve endometriosis diagnosis and management. The information from the workshop will be used to develop a management plan prototype for endometriosis and CPP for general practitioners and consumers.

By bringing together the GPs, health professionals, consumers and stakeholders, the facilitators can draw on these perspectives' experiences, insights and preferences to contribute to developing the Endometriosis Management Plan. Discussions will focus on a management plan that supports the navigation of diagnosis, facilitates management in primary care settings, enhances GP and patients' experiences, and improves the health outcomes for affected patients.

The co-design workshop will be held via Zoom on Thursday, 5 October 2023, for 4 hours. Participants will include GPs, health professionals (e.g., nurse practitioners, gynaecologists), consumers (people with endometriosis or CPP), and key stakeholders, as well as the Endo-MP Management Team, and Governance Committees (Steering Group members, and GP Advisory Group). With consent, the co-design workshop will be audio recorded to assist with transcription and the analysis of findings.

### **Why were you chosen for this research?**

We are sending you this Explanatory Statement because you have been identified by SPHERE or partner organisations as someone who may have experience with or relevant insights from a stakeholder perspective into endometriosis or chronic pelvic pain, a personal contact of the Endo-MP investigators or a participant in a previous research study who had indicated a willingness to be contacted about further research.

### **Source of funding**

This project is funded by the Commonwealth of Australia, Department of Health and Aged Care, as part of the National Action Plan for Endometriosis. There are no declarable conflicts of interest

### **Consenting to participate in the project and withdrawing from the research**

You may express your interest in participating in this project or, if you have any questions, by emailing the Endo-MP team ([endo-mp@monash.edu](mailto:endo-mp@monash.edu)). Following this, a research team member will contact you via the details provided to confirm eligibility and any questions.

Participation in this study is completely voluntary. You are not under any obligation to participate. If you agree to participate, you can withdraw from the study at any time without adverse consequences. There will be no negative consequences associated with refusal or withdrawal from participation.

### **Possible benefits and risks to participants**

The co-design workshop aims to determine the key elements for developing and implementing an Endometriosis Management Plan (EMP) to support navigation and management of endometriosis and chronic pelvic pain for providers and patients. This research will facilitate the design of an endometriosis management plan prototype that aligns with the needs of consumers and health professionals and has a high degree of utility in primary care. A management plan is expected to reduce the delay between symptom onset and diagnosis, streamline referrals and transition between services, increase awareness of the impact of endometriosis, and increase efficiency in service delivery.

Whilst there may be elements of self-reflection throughout the co-design workshop, it is unlikely that participants will be at risk of psychological distress any more than that encountered during

usual daily life. We don't anticipate that participants will become distressed by participating in the study. However, if they do become distressed when discussing their experience of endometriosis or chronic pelvic pain during the workshop, and wish to leave the discussion, they can exit the zoom meeting at any time. The workshop facilitator will contact the participant after the workshop is finished (the same day if possible) to ensure the participant is OK and to determine whether they require additional support. If needed, the researcher will arrange for the participant to talk with a GP/researcher who collaborates with the Endo-MP team.

Participants will also be reminded of other support services, should they be required:

- Beyond Blue: <https://www.beyondblue.org.au/> or <https://online.beyondblue.org.au/#/chat/start>
- Their local general practitioner or healthcare provider.

As detailed in the Explanatory statement, if a participant experiences any distress or discomfort after the workshop they can contact the following services for support:

- The researchers via email ([endo-mp@monash.edu](mailto:endo-mp@monash.edu)) or phone (03) 9902 4582 to discuss their concerns. If needed, the researcher will arrange for the participant to talk with a GP/researcher who collaborates with the Endo-MP team.
- Beyond Blue: <https://www.beyondblue.org.au/> or <https://online.beyondblue.org.au/#/chat/start>
- Their local general practitioner or healthcare provider.

## **Remuneration**

Consumer participants will be remunerated \$300 for their time and participation in the four-hour workshop. This will be provided approximately one week after the session in the form of an e-gift voucher.

## **Confidentiality**

All aspects of this study, including results, will be strictly confidential, and only the principal researchers will have access to information provided by participants. No individual data will be disclosed, and all data will be de-identified upon analysis and reporting. Collected data will be de-identified, thereby minimising the risk of loss of confidentiality.

## **Storage of data**

Any data collected will be stored on a secure drive on the Monash server. All electronic data (e.g. participant databases) will be password-protected and only accessible to the researchers. Where non-Monash University parties require access (e.g., project investigators from other organisations), secure data exchange methods, such as password-protected USB drives, encrypted files, or a secure cloud storage folder (e.g., Cloudstor, Onedrive), will be used. Any written data will be compiled into an MS Word document. All documents are stored on Monash University password-protected computers and disposed of after five years in line with university protocol.

## **Use of data for other purposes**

Secondary use of data increases the value of your data. The aggregated de-identified data collected may be used for purposes other than this study, where ethics approval has been granted.

## **Results**

Data from the co-design workshop will be utilised to design and identify key elements of the Endometriosis Management Plan prototype. We expect to present deidentified findings from the co-design workshop at conference(s) and publish our findings in a peer-reviewed journal. Abstracts of conference presentations relating to our study or links to journal publications can be directly shared with you via email or post. Participants can be provided a report of findings from the research by the implementation team upon finalisation and publication of results. Participants can contact the Endo-MP team via email ([endo-mp@monash.edu](mailto:endo-mp@monash.edu)) or phone (03) 9902 4582 to request a copy of the published results.

### **Complaints**

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics Committee (MUHREC):

Executive Officer  
Monash University Human Research Ethics Committee  
(MUHREC)  
Room 111, Chancellery Building D, 26 Sports Walk, Clayton  
Campus  
Research Office  
Monash University VIC 3800

Tel: +61 3 9905 2052  
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Email: [muhrec@monash.edu](mailto:muhrec@monash.edu)

Thank you,



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