

Consumer and health professionals' views on multidisciplinary team care for endometriosis in Australia: a co-designed patient-centred survey

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Introduction:

Endometriosis is chronic, complex, whole-body disease. Symptoms of endometriosis are heterogeneous and can change over time. Diagnosis and treatment does not follow a one-size-fits-all system, with both surgery and medical management routinely utilised. However, even after receiving treatment, many patients continue to experience poor quality of life.

Given the multi-system nature of the disease and the potential for significant negative impact on quality of life, there has been a long-standing recognition of the need for multidisciplinary care for people with endometriosis. However, there is paucity to the data supporting this approach, and much of the evidence is anecdotal.

Aim:

To co-design a survey that will improve our understanding of patient and health professional experience of past and present endometriosis multidisciplinary care in Australia.

Materials & Methods:

A diverse advisory group was assembled (Table 1). One patient representative participated in the advisory group, we also highlight that the other groups also included people with a lived-experience of endometriosis.

Table 1: Members of the advisory group

| Expertise | | Number |
|---------------------------|--|--------|
| Clinician | Gynaecologist, general practitioner, radiologist, colorectal surgeon, pain specialist and endometriosis nurse. | 7 |
| Allied health | Physiotherapist, dietitian, psychologist and occupational therapist. | 5 |
| Academic researcher | Endometriosis | 2 |
| Person with endometriosis | | 1 |

The advisory group met (virtually) to co-design a patient-centred survey to capture qualitative information from both consumers and health professionals.

Conclusion & Impact:

Our co-designed surveys will help to understand the perspectives of both patients and health professionals on multidisciplinary team care for endometriosis. The information gathered from these surveys will inform evidence-based consensus statement(s) and a proposed model for endometriosis multidisciplinary care in Australia.

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Results:

- Two qualitative surveys were co-designed to capture data from consumers and health professionals' on endometriosis multidisciplinary care.
- Surveys were refined until all advisory group members endorsed the final version(s).
- Final themes are listed below.

Table 2: Survey themes

| Themes |
|---|
| The make-up of the multidisciplinary team |
| The model of care |
| Types of resources for growing knowledge |
| Setting goals and assessing change |
| The physical environment of clinic |
| Basic sociodemographic information |

- The same questions were included in both surveys, where possible, with appropriate language modifications.
- The surveys will be distributed online following expressions of interest (n = 20 per group), followed by qualitative analysis.