





## SHORT COMMUNICATION

## Endometriosis research priorities in Australia

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In Australia, endometriosis affects one in nine women and those assigned female at birth. Although endometriosis is more common than conditions such as diabetes, research funding for endometriosis research has historically been low in comparison. The National Action Plan for Endometriosis is an Australian Federal Government initiative designed to redress this imbalance, with a focus on research funding. Identification of research priorities, and subsequent funding allocation that is determined by consumer input is vital. An online survey focusing on Australia and New Zealand found that the highest general priorities were the treatment and management of endometriosis and its cause(s).

## KEYWORDS

endometriosis, research, Australia, priorities, pelvic pain

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## INTRODUCTION

Endometriosis affects around one in nine Australian women and those assigned female at birth by the age of 44,<sup>1</sup> with at least 830 000 people in Australia likely to be affected. Despite a prevalence greater than diabetes,<sup>2</sup> and a cost of illness burden of over 9.5 billion AUD per year,<sup>3</sup> historically there has been a significant disparity in the amount of funding and resources allocated in comparison to other conditions with similar prevalence.<sup>4</sup>

In 2018 the Australian government established a national action plan for endometriosis<sup>5</sup> with funding allocated for a variety of goals including increasing awareness, educational programs, and research into early detection, causes, and effective treatments. In addition, organisations such as Endometriosis Australia have also independently raised funds for endometriosis research.

Health consumers are both the funders and beneficiaries of medical research. Involving lay people/health consumers in co-creation of research is not only an ethical imperative but also a means to improve the process of research and increase implementation and impact.<sup>6</sup> In addition, it is important to ensure that funding allocation is consistent with the priorities set by those with endometriosis themselves<sup>7</sup> as these may differ to those of researchers and clinicians.<sup>8</sup> Given that endometriosis affects not only those with the condition but also their families, friends and romantic/sexual partners,<sup>9</sup> it is prudent to also solicit their input.

The aim of this survey was to determine the general research priorities and specific priority areas of Australian people with endometriosis, their family members, partners and friends.

## MATERIALS AND METHODS

### Survey design

The survey collected anonymous demographic information including age, home address by state or territory in Australia, all of New Zealand or a country other than Australia or New Zealand. Type of location was defined by Australian Bureau of Statistics according to population size.<sup>10</sup> Participants were asked to identify if they were a person with endometriosis, the partner of a person with endometriosis, a family member of a person with endometriosis or a friend of a person with endometriosis. Members of the Endometriosis Australia closed Facebook group were polled to determine areas of interest for endometriosis research, with responses collated and forwarded to the Endometriosis Australia Medical Advisory Committee. The identified areas of interest were converted to specific research questions by the Medical Advisory Committee and added to a set of previously identified research priorities.<sup>11</sup> Survey respondents were asked to rank the 16 identified research areas in order of importance from (most important) to 16 (least important). These 16 research areas were made up of five general priority areas and 11 specific priority areas. Design and distribution of the survey was approved by the board of Endometriosis Australia as part of its research support objectives

to ensure that the wishes of patients were aligned with the research support from fundraising.

### Participants and recruitment

The survey was circulated via Endometriosis Australia's social media platforms (Facebook, Instagram) and through Endometriosis Australia's mailing list as a link. The survey was available for three weeks between 10 November to 3 December 2019. Reminders were sent to complete the survey with notices that patients, partners, carers, family and friends could participate.

### Data and analysis

Data were analysed using SPSS v24 (IBM Corporation, Armonk, NY, USA). Descriptive statistics were presented as means and standard deviations (for normally distributed data) or number and percentages (for categorical data). Inferential statistics for between-group comparisons for differences in categorical variables were analysed via  $\chi^2$ . Statistical significance was set at  $P < 0.05$ . Missing data were not replaced.

## RESULTS

There were 1169 valid responses received, 1067 from those with endometriosis (91.3%), 55 from family members (4.7%), 28 from partners (2.4%) and 19 from friends (1.6%). [Table 1](#) outlines the demographics of the respondents.

The prioritisation of the five general research priority areas was consistent irrespective of the category of respondent for the two highest priorities. The highest priority across all respondents was 'What are the best ways of treating endometriosis and managing its symptoms?' – rated as the highest priority by 39% (95% CI 35.5–41.4) of those with endometriosis, 30% (95% CI 19.2–42.9) of family members, 54% (95% CI 35.8–70.5) of partners and 32% (95% CI 15.2–54.2) of friends. The second highest priority was 'What are the causes of endometriosis?', with 33.6% (95% CI 30.9–36.5) of those with endometriosis, 24% (95% CI 14.5–37.0) of family members, 36% (95% CI 20.6–54.2) of partners and 32% (95% CI 15.2–54.2) of friends rating this as the highest priority. The third highest priority 'What are the best ways of early diagnosis of endometriosis without surgery?' showed some differences between groups with 19% (95% CI 16.9–21.7) of those with endometriosis, 35% (95% CI 23.8–48.5) of family members, 7% (95% CI <1% to 23.7%) of partners and 26% (95% CI 11.5–49.1) of friends rating this as the highest priority area. Neither 'What are the fertility implications of endometriosis?' nor 'How does endometriosis impact the individual and society?' were considered high priority, with just 6% and 2% of those with endometriosis respectively, considering these as high priority.

Interestingly the specific priority questions did not necessarily mirror those of the more general research priority areas. [Table 2](#) outlines the specific priority areas for those with endometriosis.

**TABLE 1** Demographics of survey respondents

	Person with endometriosis <i>N</i> = 1067		Family member <i>N</i> = 55		Partner <i>N</i> = 28		Friend <i>N</i> = 19	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Age								
<15 years	6	0.56	21	38.18	0	0	0	0
15–24 years	218	20.43	5	9.09	5	17.86	6	31.58
25–34 years	463	43.39	7	12.73	9	32.14	7	36.84
35–44 years	294	27.55	4	7.27	10	35.71	2	10.53
45–54 years	86	8.06	17	30.91	2	7.14	2	10.53
>55 years	0	0	1	1.82	2	7.14	2	10.53
Area of residence								
Australian Capital Territory	36	3.37	1	1.85	3	10.71	2	10.53
New South Wales	311	29.15	23	42.59	7	25	9	47.37
Northern Territory	9	0.84	0	0.00	1	3.57	1	5.26
Queensland	194	18.18	12	22.22	4	14.29	0	0
South Australia	98	9.18	6	11.11	3	10.71	2	10.53
Tasmania	37	3.47	4	7.41	0	0	1	5.26
Victoria	280	26.24	5	9.26	9	32.14	2	10.53
Western Australia	66	6.19	3	5.56	1	3.57	0	0
New Zealand	4	0.37	0	0	0	0	1	5.26
A country other than Australia or New Zealand	30	2.81	0	0	0	0	1	5.26
Blank	2	0.19	0	0	0	0	0	0
Type of location								
Location of less than 10 000 people	134	12.56	8	14.81	1	3.57	1	5.26
City of between 10 000 and 100 000 people	206	19.31	15	27.78	5	17.86	3	15.79
Large metropolitan city (>100 000 people)	273	25.59	14	25.93	6	21.43	4	21.05
Capital city	454	42.55	17	31.48	16	57.14	11	57.89

There were no differences in general research priority areas based on the type of location where the respondent lived ( $P > 0.05$  for all priority comparisons).

## DISCUSSION

Our findings show that effective treatment, and the cause(s) of endometriosis, are the most important general research priority areas among Australians and New Zealanders with endometriosis, their families, partners and friends. This is in line with previous priority-setting work in international populations.<sup>8,11,12</sup> Compared to friends and family members, those with endometriosis and their partners were less likely to prioritise early diagnosis over treatment and causes. This may be due to the fact that for those with endometriosis, pain tends to be poorly controlled and pain severity tends to be a key factor in low quality of life<sup>13</sup> and lost productivity.<sup>3</sup> This is similar for partners, who tend to feel that symptom severity affects their day-to-day life.<sup>14</sup>

Unexpectedly, the priorities for the general research areas were not necessarily reflected in the specific research questions that

respondents wanted to be prioritised and it is unclear why the ratings diverged. While fertility implications and societal impact were ranked low in general research areas, the research questions related to the impact of moderate to severe endometriosis on fertility and the financial burden of living with endometriosis were high priority questions. Given the significant financial burden associated with the treatment of endometriosis in Australia,<sup>3</sup> and the significant out-of-pocket costs of multidisciplinary management,<sup>15</sup> it is not surprising that fertility and societal impact are viewed as high priority areas. Given the conflicting information Australian women are given regarding endometriosis and fertility,<sup>16</sup> and the concerns this brings to many women and their partners,<sup>17</sup> it is understandable that this may be a significant unanswered question for many.

Other priorities were related to a number of unanswered questions in the literature, including modifiable causes/risk factors for endometriosis, the result of repeat surgeries on endometriosis outcomes,<sup>18</sup> early or non-invasive detection, and the usage of medicinal cannabis, a treatment that shows potential for endometriosis<sup>19</sup> but still requires significant further research. Interestingly, despite the potential effectiveness of dietary interventions,<sup>20</sup> this was not considered a high priority.

**TABLE 2** Research priority area ranking

Priority area	Median (interquartile range) (1 highest priority, 11 lowest priority)
Does repeat surgery for endometriosis improve patient outcomes?	3 (2–6)
What is the effect of moderate–severe endometriosis on fertility?	4 (1–7)
What early life factors may predispose to endometriosis?	4 (2–6)
What is the financial burden of living with endometriosis?	5 (2–8)
Can ultrasound reliably detect early endometriosis without surgery?	5 (3–7)
Is there a blood test that could screen for endometriosis early?	5 (3–7)
What is the efficacy of using medical cannabis for endometriosis associated symptoms?	6 (4–8)
What is the quality of life and psychological impact of endometriosis?	7 (3–8)
What is the effect of diet and lifestyle interventions (like engaging in regular, graded exercise) on the symptoms of endometriosis?	8 (5–10)
What is the efficacy of using melatonin for endometriosis associated symptoms?	9 (6–9)
What is the impact of endometriosis on delivery and birth outcomes?	11 (7–11)

Given the consistency between priority areas reported by our study and those in other countries, it is likely that these represent a common core of collective concerns, and that prioritising research and funding to treatment and the cause(s) of endometriosis is likely to have a wide-ranging, rather than solely local, benefit.

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