



New Research Reveals Research Priorities of Australians affected by Endometriosis

14 June 2023

A new research survey has revealed that the highest priorities among those with endometriosis, their family and friends across all respondent categories was "What are the best ways of treating endometriosis and managing its symptoms?", supported by 39% of individuals with endometriosis, 30% of family members, 54% of partners, and 32% of friends. The second highest priority was "What are the causes of endometriosis?", with 33.6% of individuals with endometriosis, 24% of family members, 36% of partners, and 32% of friends considering it the highest priority.

According to co-author Donna Ciccia, Master of Research candidate at NICM Health Institute and Co-founder of Endometriosis Australia, the priorities identified in the survey of people with endometriosis clearly indicated that there was a broad range of areas that still need urgent attention, despite the national action plan being released five years ago.

In 2018 the Australian government established a National Action Plan for Endometriosis (NAPE) with funding allocated for a variety of goals including increasing awareness and educational programs. However, Endometriosis Australia, a charity established 10 years ago to support the 1 in 9 girls, women and AFAB with endometriosis, is yet to receive any government funding.

"It is crucial that those with endometriosis have their voices heard when deciding what areas should be funded, whether by the government or other funders. Endometriosis Australia is the largest non-government funder of research in Australia, through donated funds." she continued.

"It is clear that those with endometriosis need educational resources to learn, what are the best ways of treating endometriosis and managing its symptoms? Endometriosis Australia calls on the Federal Government to urgently prioritise patients and fund our best practice, empirically sound information for patients, nurses, GPs, allied and complementary health practitioners", Ms Ciccia said. "We are moving onto the new NAPE while help for the support of the endometriosis community hasn't even been allocated, let alone spent, from the old one."

Associate Professor Mike Armour from Western Sydney University, the lead author on the study and Chair of Endometriosis Australia's Research Committee, said, "We have welcomed government investment in endometriosis research, but until now there has been a lack of understanding of what areas people with endometriosis in Australia wanted to be prioritised. This survey highlighted specific priority areas, including the impact of endometriosis on fertility, outcomes from repeated surgeries, factors predisposing people to endometriosis, non-invasive detection methods, and the efficacy of medical cannabis for endometriosis-associated symptoms. These priorities indicate the need to address a wide range of unanswered questions and concerns in endometriosis research."

"It is encouraging that many areas that Australian researchers are currently working on align with those prioritised by the community. Australia punches above its weight internationally when it comes to endometriosis research, but these findings are a timely reminder that we still have a lot of work to do." Assoc. Prof Armour said.

New research has now been published in the *Australian and New Zealand Journal of Obstetrics and Gynaecology* <https://obgyn.onlinelibrary.wiley.com/doi/epdf/10.1111/ajo.13699>