



RAISE YOUR VOICE

QENDO SURVEY SNAPSHOT 2024

In 2024, QENDO celebrates our 36th year of community voices and stories. This survey is distributed nationally through organisations and partners and aims to identify people affected by endometriosis and pelvic pain's experiences, concerns and aspirations.

667
VOICES
aged 14 - 76



- 91% identified as female
- 38% live in a metro area
- 31% live in a rural or regional area
- 17% live with a disability
- 13% identified as LGBTIQ+
- 6% identified as CALD+
- 2% identified Aboriginal and/or Torres Strait Islander

EARLY DIAGNOSIS AND SYMPTOMS RECOGNITION

EDUCATION FOR MEDICAL PROFESSIONALS

COMPREHENSIVE TREATMENT & MANAGEMENT

SUPPORT FOR PATIENTS

ACCESS TO SPECIALISTS AND TREATMENT OPTIONS

"Treatment is not just surgery and then done. We need ongoing support without having to beg for help."

Top issues identified in Australia today



82%

Unable to attend work due to their endometriosis in the last year



85%

Unable to attend social function due to their endometriosis in the last year



92%

Reported endometriosis had impacted their mental health



93%

Reported their ability to exercise was impacted due to endometriosis



86%

Reported their eating habits were impacted due to endometriosis



89%

reported impacts on their ability to manage day to day

Top 5 **needs** for people with endometriosis and pelvic pain:

1 Financial Support and Affordable Healthcare

- Financial aid for specialist appointments, treatments, and medications.
- Access to affordable or free medical, mental health, and allied health services.
- Government subsidies or Medicare coverage for surgeries and treatments.

2 Medical Understanding and Training

- Improved recognition and understanding of endometriosis symptoms among healthcare professionals.
- Enhanced education and training for doctors and specialists.

3 Pain Management and Mental Health Support

- Non-stigmatised access to pain relief and mental health counselling.
- Availability of pain specialists and effective pain management options.

4 Workplace Support and Legal Protections

- Legal protections against workplace discrimination related to endometriosis.
- Supportive employers offering flexible work arrangements and additional sick leave.

5 Integrated and Holistic Care

- Access to multidisciplinary care including dietitian, physical therapists, and other specialists.
- Improved coordination among healthcare providers for comprehensive care plans.

"It shouldn't always be about fertility. I just want to manage my condition to be able to enjoy daily life and be able to sleep pain-free."

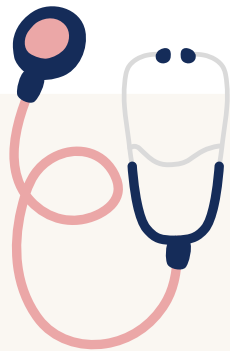
"A medical practitioner finally listening to all of my long story, and taking my pain seriously, helped massively improve my mental health, stress, and symptoms after months of what was in hindsight gaslighting."

"It is very hard to explain gaps in my resume due to time I have had to take off because of pelvic pain."



71%

Spent **\$5000.00** or more on symptom management in the last year



99%

Visited a **GP** in the last 12 months



95%

Would utilise new treatments if available on the Pharmaceutical Benefits Scheme (PBS)

FATIGUE
BLOATING

Your most reported symptoms in addition to pelvic or period pain

LOW IRON
MIGRAINES



We recommend that Australian Governments, sector, industry and organisations focus on the following priority areas as key-away messages from the endometriosis and pelvic pain community survey.

Be Taken Seriously

Patients value doctors who take their symptoms seriously, emphasising the need for improved medical understanding.

Educating Healthcare Professionals

We call for better education and training to address gaps in medical knowledge.

Impact on Quality of Life

Endometriosis significantly affects mental health and daily life, necessitating comprehensive support.

Financial Challenges

High costs of treatment pose a significant burden, highlighting the need for financial assistance.

Targeted research

Increase funding for research about targeted treatment and types of endometriosis.

Support Service and Peer Programs

Connecting with services and peers within free community services to build capacity, understanding and our toolbox.

We thank each and every person who shared their experience and story with our community snapshot survey. Your responses are delivered within this public report which will continue to be tabled and inform care, research and policy in Australia.

If you are affected by endometriosis or pelvic pain and need someone to talk with, you can call the QENDO support line on 1800 ask QENDO or access our free services at www.qendo.org.au