

Perspectives of Endometriosis Patients and Practitioners on Improving Future Care

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1. About Endometriosis

Endometriosis is a disease where tissue like the uterus' lining is found outside of the uterus (1) (Figure 1). Up to 14% of people presumed female at birth will have endometriosis in their lifetime (2). Unresolved pain impacts 70% of patients (3), costing huge sums in healthcare costs, and productivity losses (4). Endometriosis is incurable, and patients face long delays to diagnosis (5).

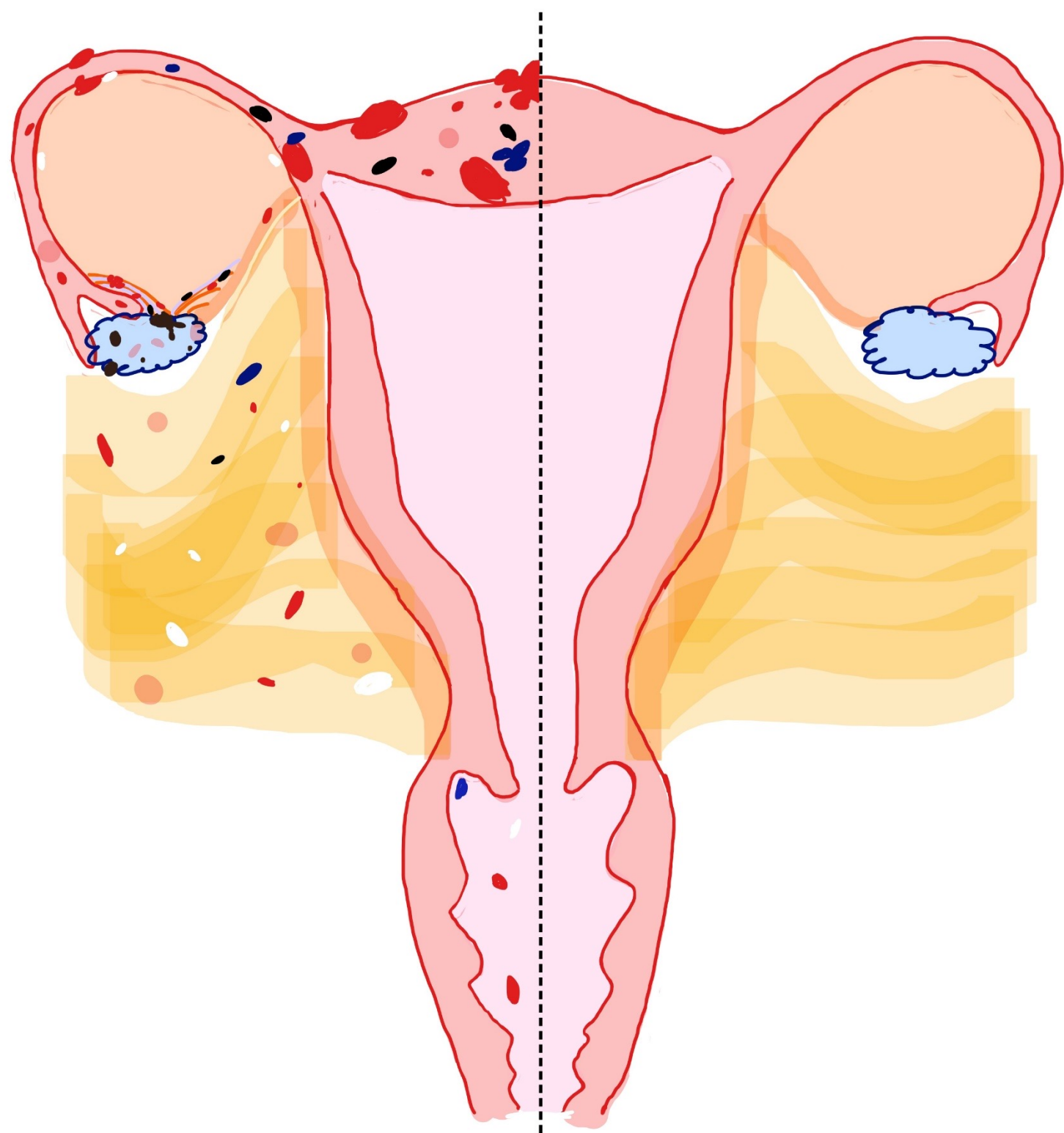


Figure 1: Schematic representing endometriosis.

2. Priorities and Experiences of NZ Endometriosis Patients

Priorities: 1262 endometriosis patients and their whanāu took part in a short survey to rank their research priorities. Their top priority was the development of novel management options, predominantly the production of a cure.

Experiences: Amongst the 1024 endometriosis patients with confirmed diagnoses, the average diagnostic delay was 9.7 ± 7.1 years, which varied throughout the country (Figure 2).

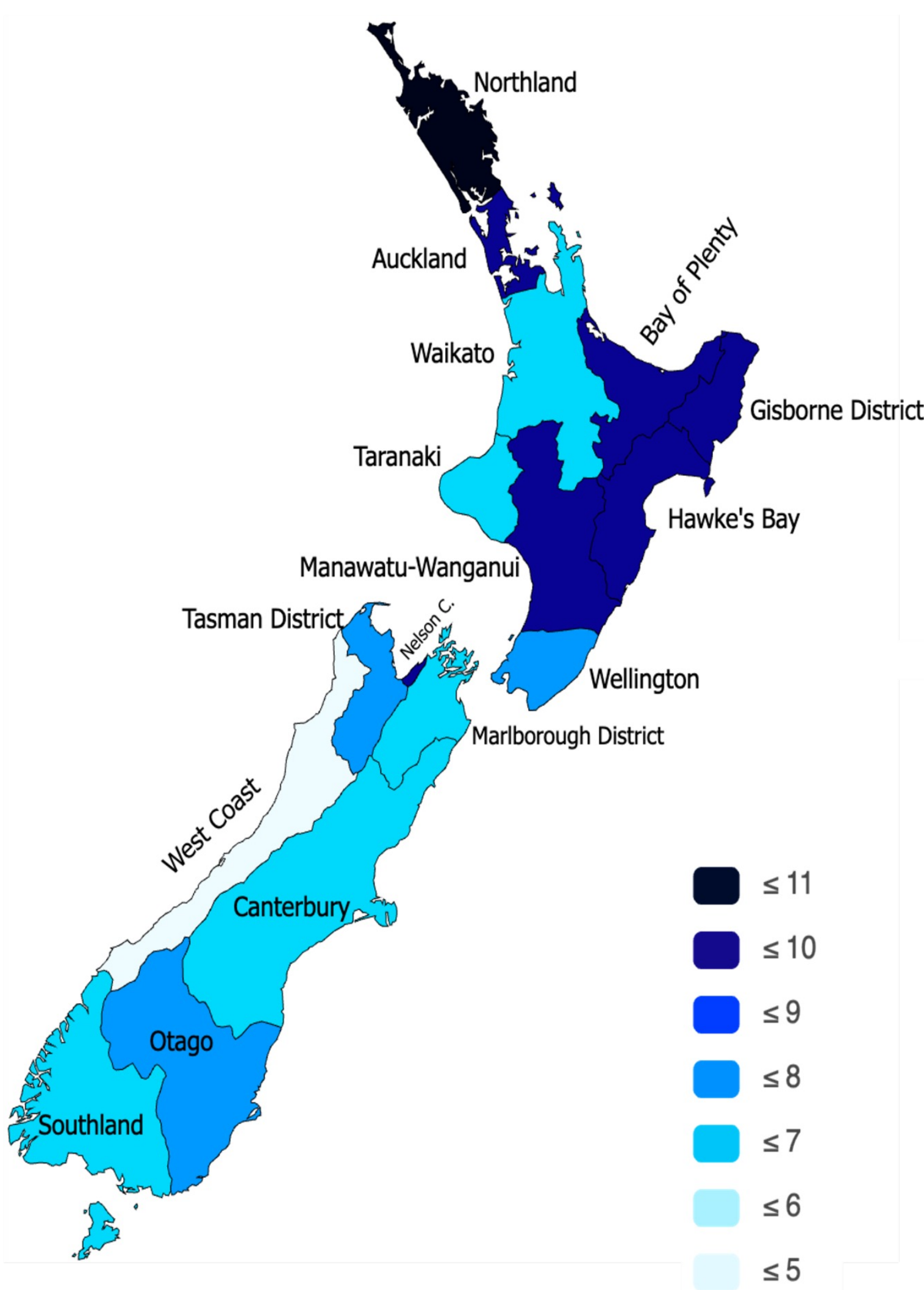


Figure 2: Median diagnostic delay by region.

3. Perspectives of Endometriosis Patients

Three cohorts of endometriosis patients were recruited for anonymous, asynchronous, text-based online discussions about their experiences:

- 27 Māori patients.
- 10 Pasifika patients.
- 28 LGBTQIA+ patients.

Themes apparent in all three cohorts included the:

- Normalisation of pain and dismissal.
- Value and difficulty of diagnosis.
- Power of practitioners over patient lives.

“I wish I fought for myself more instead of just letting doctors dismiss me”

References: 1. World Health Organisation. Endometriosis: World Health Organisation; 2023 [Available from: <https://www.who.int/news-room/fact-sheets/detail/endometriosis>]. 2. Australian Institute of Health and Welfare. 1 in 7 Australian women aged 44-49 have endometriosis: AIHW; 2023 [Available from: <https://www.aihw.gov.au/news-media/media-releases/2023/2023-september/1-in-7-australian-women-aged-44-49-have-endometriosis>]. 3. Agarwal SK, Foster WG, Groessl EJ. Rethinking endometriosis care: applying the chronic care model via a multidisciplinary program for the care of women with endometriosis. Int J Womens Health. 2019;11:405-10. 4. Soliman AM, Coyne KS, Gries KS, Castelli-Haley J, Snabes MC, Surrey ES. The Effect of Endometriosis Symptoms on Absenteeism and Presenteeism in the Workplace and at Home. J Manag Care Spec Pharm. 2017;23(7):745-54. 5. Tewhiti-Smith J, Semprini A, Bush D, Anderson A, Eathorne A, Johnson N, et al. An Aotearoa New Zealand survey of the impact and diagnostic delay for endometriosis and chronic pelvic pain. Scientific Reports. 2022;12(1):4425.

4. Approaches of GPs

185 general practitioners (GPs) took part in an online survey outlining their approach to endometriosis management and potential benefits of the inaugural 2020 Diagnosis and Management of Endometriosis in New Zealand Guidelines.

Within this cohort:

- Only 35% had read the guidelines.
- 72.5% had weekly gynaecology consults.
- GPs emphasised progestin therapies and dissuaded surgery in approaching treatment.
- A minority suggested inappropriate approaches (opioids and pregnancy).

5. Interviews with GPs

Nine GPs were interviewed about their perspectives of endometriosis care. They highlighted:

- New Zealand's health system is overloaded which is hard on practitioners and patients.
- GPs can only help patients who present to the clinic and are forthcoming about their issues.
- Patient journeys are impacted by dismissal, trivialisation and diagnostic difficulties.
- Comprehensive system changes are required to significantly improve endometriosis care.

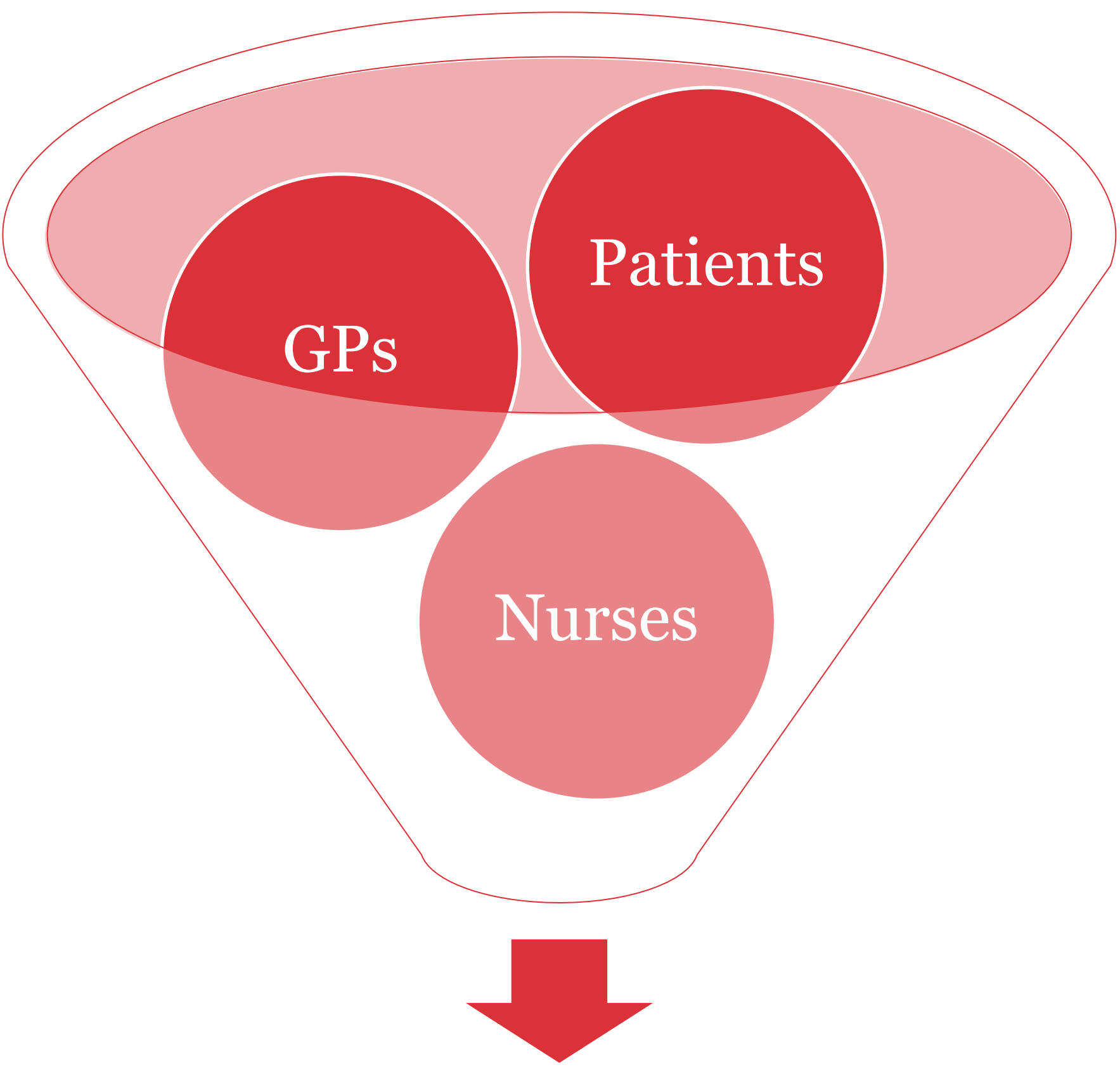
“The difficulty of diagnosis compromises patient care for people with endometriosis”

6. Future Steps

Patients highlight they want more treatment options, and practitioners who are endometriosis specialists. GPs identify a key solution for improving endometriosis management is to have endometriosis nurse specialists. Therefore:

1. To explore this approach, an online survey and interviews will be conducted with New Zealand nurses to gather their opinions, identify their interest in endometriosis specialisation training and gather input into the training approach.
2. Research findings will be made available to improve the current national endometriosis management guidelines which are short and out-of-date by international standards.

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Characterisation of present issues with endometriosis care approaches, and potential solutions for integration into future national guidelines for endometriosis management.