



## Introduction

There are 176 million women worldwide with endometriosis.<sup>1</sup> 1 in 9 Australian women. 34,200 Australian hospitalisations occurred in 2016-17.<sup>2</sup> Seven years average of the time to a diagnosis. In Australia there is a \$7.4 billion economic cost burden annually 2017-18.<sup>2</sup> Historical neglect and systemic failure to act on endometriosis and women's health has seen an Australian National Apology.<sup>3</sup> A National Action Plan for Endometriosis recognises the magnitude and urgency of endometriosis concerns.<sup>3</sup>

## Aims

To synthesise and expose the collective experiences of women and their endometriosis diagnosis journeys.

## Methodology

A qualitative thematic analysis of 49 women's publicly available endometriosis diagnosis experiences online. Major themes were manually coded in NVIVO. Results were displayed in a series of descriptive thematic maps, a short report of results and article.

## Recommendations

- ♀ GP and specialist education.
- ♀ Community and GP recognition that endometriosis symptoms can start early in a girl's life.
- ♀ Education and community awareness campaigns for women of all ages on social media and in schools.
- ♀ Prioritising Endometriosis Nurse Practitioners to decrease load on doctors and emergency departments.
- ♀ GP and patients to be working together in positive partnerships.
- ♀ GP's to be an ally and "that one doctor" women need in their healthcare.

## Conclusions

Women highlighted the positive impact of "that one doctor" who said the word "endometriosis" who listened, believed, investigated and provided prompt referral to specialists. Diagnosis gave relief and answers to the long journey, provided women with a sense of community, hope and personal visibility after feeling alone.

"That one doctor" can transform a patient's experience and create a positive endometriosis diagnosis pathway. Symptom dismissal with long diagnosis delays are having negative, physical and psychological consequences for women. Early detection, GP education and community awareness campaigns are imperative to reduce further delayed diagnosis and long-term negative impacts of undiagnosed endometriosis.

## Recommended Endometriosis Diagnosis Pathway



## Results



**Figure 1.**  
Effects of non-diagnosis

**References:**  
 1. Endometriosis.org. About endometriosis [Internet]. Date cited 1/10/19. Available from: <http://endometriosis.org/resources/articles/facts-about-endometriosis/>  
 2. Australian Institute of Health and Welfare. Endometriosis in Australia: prevalence and hospitalisations. Canberra: AIHW; 2019.  
 3. Commonwealth of Australia. National Action Plan for Endometriosis. Canberra, Department of Health. Australia; 2018

**Acknowledgements:**  
 Special thanks to the 49 women who shared their experiences in hope of making a difference. Ms. Jane Lynch and Ms. Wendy Dawson (Epworth HealthCare) and Mr. Adam Ferrier, Prof. Sandra Leggat, Ms. Shannon Checklin (La Trobe University) for all your encouragement and support throughout my project.