

## Should endometriosis be managed within a chronic disease framework? An analysis of national policy documents

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### Abstract

**Objective.** The aim of this study was to determine whether endometriosis meets the definition for chronic disease in Australian policy documents.

**Methods.** A qualitative case study approach was used to thematically analyse the definitions contained in Australian chronic disease policy documents and technical reports. The key themes were then compared with descriptions of endometriosis in peer-reviewed literature, clinical practice guidelines and expert consensus statements.

**Results.** The search yielded 18 chronic disease documents that provided a definition or characteristics of chronic disease. The thematic analysis identified key elements of chronic diseases pertaining to onset, causation, duration, treatment, disease course and impact (individual and societal). A comparison with endometriosis descriptions indicated that endometriosis meets five of the six chronic disease key elements.

**Conclusion.** In Australia, long-term and complex conditions are managed within a chronic disease framework and include mechanisms such as chronic disease management plans (CDMPs) to assist with coordination and management of these conditions. Because endometriosis has most of the characteristics of chronic disease, it could potentially be reframed as a chronic disease in endometriosis clinical practice guidelines and consensus statements. Further, the use of CDMPs may provide a mechanism to promote individualised care and multidisciplinary management of this chronic, enigmatic and debilitating disease.

**What is known about the topic?** In Australia, long-term complex diseases can be managed within a chronic disease framework that include mechanisms for coordinated care such as CDMPs and team care arrangements. Endometriosis is described as an inflammatory, progressive, relapsing and, for some women, debilitating condition, but is rarely described as a chronic disease in the clinical practice guidelines and consensus statements available in Australia.

**What does this paper add?** Endometriosis shares most of the characteristics of a chronic disease so may benefit from chronic disease management systems such as CDMPs.

**What are the implications for practitioners?** CDMPs may be a useful mechanism to coordinate and improve the effectiveness of care for women with endometriosis who experience sustained symptoms of endometriosis.

**Additional keywords:** chronic conditions, chronic disease management plan, chronic illness, endometriosis treatment.

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### Introduction

The World Health Organization (WHO) defines non-communicable diseases (also referred to as chronic diseases) as diseases that are not passed from person to person and are typically of a long duration and slow progression.<sup>1,2</sup> In Australia, long-term,

complex diseases can be managed within a chronic disease framework. This includes mechanisms for coordinating care, such as the chronic disease management plan (CDMP) and team care arrangement (TCA) for people with chronic disease who require ongoing care.<sup>3</sup> To be eligible for a CDMP, a general

practitioner (GP) must determine that the condition 'has been (or is likely to be) present for six months or longer'<sup>3</sup> and the patient would benefit from a structured approach to management. The use of a CDMP is not restricted to specific conditions provided patients meet the eligibility criteria above. A TCA can also be developed to support multidisciplinary care, allowing people with chronic disease to access five subsidised allied health services in a calendar year.<sup>4</sup>

CDMPs and TCAs have been implemented for patients with chronic diseases such as diabetes.<sup>5-7</sup> Health service research has investigated the effects of these plans on care coordination, clinical outcomes and patient experiences.

In terms of care coordination for diabetes, Zwar *et al.*<sup>7</sup> reported an increase in multidisciplinary care (care provided by at least two other providers, including one diabetes-specific provider) and of GP adherence to performing diabetes-specific checks per clinical guidelines for diabetes management when care plans were implemented. Wickramasinghe *et al.*<sup>6</sup> also reported process improvements, including an increase in GPs conducting diabetes annual cycle of care checks.

Furthermore, for those with diabetes, an improvement in clinical outcomes, such as cholesterol, blood pressure and HbA1c, was reported among those receiving multidisciplinary care in the study by Zwar *et al.*<sup>7</sup> Similar improvements in clinical outcomes, such as improvement in cholesterol, HbA1c and body mass index, were reported by Wickramasinghe *et al.*<sup>6</sup>

In terms of patient experience, a cluster randomised controlled trial involving 60 practices in Australia indicated that patients with a TCA assessed the quality of their care with their general practice clinic more favourably than those that did not have a TCA.<sup>5</sup> Thus, there may be benefits to be realised for managing other complex and long-term conditions with the use of CDMPs.

Endometriosis is an inflammatory condition characterised by endometrial-like tissue growing outside the uterus, which can result in pain and adhesions.<sup>8,9</sup> Endometriosis commonly grows on the pelvic organs and peritoneum, but has been found in other parts of the body, such as the lungs, diaphragm, kidney and navel.<sup>8,9</sup> The gold standard for diagnosing endometriosis is through laparoscopy, with confirmation of the disease made through histological examination of specimens collected during the surgical procedure.<sup>10</sup> There is no cure, so long-term management is required using medical (e.g. hormone treatment and analgesics) and/or surgical treatment (e.g. excision surgery), both of which focus on alleviating symptoms.<sup>11</sup> Clinical practice guidelines and consensus statements describe endometriosis as common,<sup>11,12</sup> enigmatic,<sup>11</sup> relapsing<sup>11</sup> and, for some women, debilitating.<sup>11</sup>

Although endometriosis is a persistent and long-term condition, to the authors' knowledge endometriosis has not been formally identified as a chronic disease at the international, US, UK, Canada, New Zealand or Ireland policy level. The International Association for the Study of Pain includes endometriosis in the Classification of Chronic Pain Conditions (Codes 763.X8 and 795.X8).<sup>13</sup> In the UK, women with endometriosis were eligible to participate in a chronic disease self-management program called the Expert Patient Program.<sup>14</sup> This program is funded by the Department of Health and has been implemented in health organisations such as

Endometriosis UK,<sup>15</sup> community settings<sup>16</sup> and across the National Health Service.<sup>14</sup>

In Australia, only one<sup>11</sup> of the four guidelines and consensus statements available for clinical guidance labels endometriosis as a chronic disorder. The aim of the present study was to identify how chronic diseases are defined in Australian national policy documents and to examine whether endometriosis meets the criteria for chronic disease.

## Methods

A qualitative case study approach was selected.<sup>17</sup> This approach involves conducting an in-depth examination of a phenomenon (in this case chronic disease definitions) within its particular context (the Australian policy environment).<sup>18</sup> A two-stage process was used in the study. First, a document analysis of Australian chronic disease strategies, frameworks, fact sheets and technical and monitoring reports containing definitions or characteristics of chronic disease was undertaken in order to obtain a comprehensive understanding of how chronic diseases are defined in the Australian policy environment. Second, the key themes derived from the analysis of chronic disease definitions were applied to endometriosis peer-reviewed literature, guidelines and consensus statements to assess whether endometriosis meets the criteria for chronic disease.

### Chronic disease document analysis

This research was guided by Bowen's definition for document analysis,<sup>19</sup> which is to identify, select, appraise and analyse data from a defined set of documents. The steps undertaken in the document analysis process are summarised in Fig. 1.

#### Step 1: search for chronic disease documents

A search was performed on the Australian Government Department of Health website ([www.health.gov.au](http://www.health.gov.au), accessed 17 August 2016) to identify documents associated with chronic disease published from 2000 to August 2016. This time period captures the release of the WHO global strategy for chronic disease and subsequent action plans, to which Australia is a member state. The term 'chronic disease' was searched in the

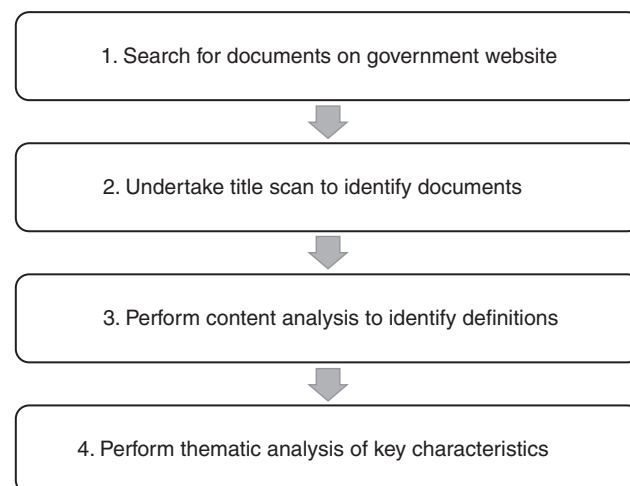


Fig. 1. Document analysis process, adapted from Bowen.<sup>19</sup>

following pages of the website: 'Health topic quick view', 'A to Z topics', 'For consumers', 'For health professionals' and 'Publications'. Where documents were a part of a series, the most recent version was included. A manual search for additional definitions was conducted from documents identified through references or attached as links on the government website.

#### *Step 2: title scan of chronic disease documents*

The titles of documents were initially scanned with documents retained if they related to chronic disease (and excluded if they related to a specific disease, for example diabetes). A document record was developed to record the details of each document, including source, year, title and web link.

#### *Step 3: content analysis to identify definitions*

A content analysis of the documents was then performed to identify definitions of chronic disease in the full text of the included documents. A record of whether the document included a definition was recorded in the document record spreadsheet. For those documents that included a definition of chronic disease, the definition was copied verbatim from the document and recorded in a separate spreadsheet (definition extraction), along with the source, date and title of the document.

#### *Step 4: thematic analysis of definitions*

The definitions that were collated from Step 3 were then thematically analysed to identify key themes of chronic disease. This process involved reviewing the extracted definitions, identifying common characteristics of chronic disease, generating

codes for these characteristics and grouping these codes into key themes.<sup>19</sup>

#### *Application to descriptions of endometriosis*

A search for endometriosis descriptions was undertaken in peer-reviewed research and endometriosis-specific guidelines and consensus statements. The endometriosis peer-reviewed research papers were identified through a Medline search of English language papers using the keyword term 'endometriosis' from 2000 to 2016. Endometriosis guidelines and consensus statements for Australia (available in August 2016) were obtained by searching the Royal Australian College of General Practitioners, Royal Australian and New Zealand College of Obstetricians and Gynaecologists, Royal Australasian College of Surgeons and Royal Australasian College of Physicians websites, and a Google search using 'endometriosis' AND 'guidelines', restricting the search to Australia. The Australian Clinical Practice Guideline portal was searched using the same terms.

The key themes derived from chronic disease definitions were then applied to descriptions of endometriosis in peer-reviewed research papers, clinical practice guidelines and consensus statements.

## **Results**

The search yielded 20 chronic disease documents, 18 of which included a definition or characteristic of chronic disease. A summary of the documents included in the thematic analysis of chronic disease definitions is given in Table 1.

**Table 1. Summary of documents for analysis**

AHMAC, Australian Health Ministers' Advisory Council; AIHW, Australian Institute of Health and Welfare; GP, general practitioner

Source	Information type
AHMAC: National Strategic Framework for Chronic Conditions (Second Draft) <sup>20</sup>	Policy framework or strategy
AIHW: Chronic Disease and Associated Risk Factors in Australia, 2001 <sup>21</sup>	Technical report
AIHW: Chronic Diseases and Associated Risk Factors in Australia, 2006 <sup>22</sup>	Technical report
AIHW: Premature Mortality from Chronic Disease <sup>23</sup>	Technical report
AIHW: Key Indicators of Progress for Chronic Disease and Associated Determinants: Data Report <sup>24</sup>	Technical report
AIHW: Contribution of Chronic Disease to the Gap in Adult Mortality Between Aboriginal and Torres Strait Islander and Other Australians <sup>25</sup>	Technical report
AIHW: Risk Factors Contributing to Chronic Disease <sup>26</sup>	Technical report
AIHW: Australia's Health 2014 <sup>27</sup>	Technical report
Department of Health: Chronic disease management – individual allied health services under Medicare: patient information <sup>4</sup>	Patient factsheet
Department of Health: Chronic disease management: patient information <sup>28</sup>	Patient factsheet
Department of Health: Chronic disease management: provider information <sup>3</sup>	Provider factsheet
Department of Health: Chronic disease management – individual allied health services under Medicare: provider information <sup>29</sup>	Provider factsheet
Department of Health: Flexible Fund Guidelines: Chronic Disease Prevention and Service Improvement Flexible Fund <sup>30</sup>	Guideline
Department of Health: Chronic Conditions <sup>31</sup>	Informational webpage and links to chronic disease strategies
Department of Human Services: Education guide – Chronic Disease GP Management Plans and Team Care Arrangements <sup>32</sup>	Guideline for practitioners
National Health and Hospitals Reform Commission: A Healthier Future for all Australians: Final Report <sup>33</sup>	Technical report
National Public Health Partnership: Blueprint for Nation-wide Surveillance of Chronic Diseases and Associated Determinants <sup>34</sup>	Framework for surveillance of chronic disease
National Health Priority Action Council: National Chronic Disease Strategy <sup>35</sup>	Policy framework or strategy

### *Chronic disease terms and definitions*

Multiple terms are used to describe chronic disease, including chronic health conditions, chronic illness, chronic disease, non-communicable diseases and long-term health conditions.<sup>20,33</sup> The most commonly used definitions were adapted from either the Australian Institute of Health and Welfare (AIHW), which identified common characteristics of chronic disease,<sup>21</sup> or the Department Health definition, which is associated with funding for chronic disease management.<sup>3</sup>

### *Thematic analysis of chronic disease definitions*

Six key themes were identified in the thematic analysis relating to onset, causation, duration, treatment, disease course and impact (Table 2).

#### *Onset*

Due to the broad nature of diseases captured by the term 'chronic disease', there was variability in conceptualisations of onset and causation in the chronic disease documents (Table 2). Five indicated that chronic diseases typically involve a long latency period.<sup>21,23,24,26,34</sup> Among the documents, two stated that chronic diseases could affect an individual at any age,<sup>20,21</sup> whereas others noted a greater prevalence in older age.<sup>20,35</sup>

#### *Causation*

Similar to onset, there was variation in conceptualisation of cause of chronic diseases (Table 2). Many of the documents acknowledged that chronic diseases have complex causality (nine documents) and may be associated with multiple risk factors (11 documents). The AIHW acknowledged there may be uncertainty around causality and progression of the disease.<sup>21</sup>

#### *Duration*

Most of the documents indicated that chronic diseases have a long duration (16 documents; Table 2), whereas others used a minimum duration, for example 'lasted or expected to last longer than six months'.<sup>3</sup>

#### *Treatment*

There was consensus among the national documents that a long-term approach was required to manage chronic diseases (Table 2).

#### *Disease course*

Most of the documents conceptualise chronic diseases as being persistent, including that they do not resolve spontaneously or have no cure. The progression of the disease may lead to a gradual deterioration in health,<sup>20,21,35</sup> other complications<sup>21,22,25,26</sup> or comorbid conditions.<sup>23</sup> However, a chronic condition, although persistent, may not be the cause of death.<sup>23,25,27,31</sup>

#### *Impact*

Conceptualisations of the impact of a chronic disease varied depending on the condition. Some were associated with premature mortality, whereas others were associated with disability or impairment.<sup>22,26,30</sup> Diverse individual and societal effects

were described, including impairments, activity limitations or disability, reduced quality of life, economic costs, lost productivity, loss of independence and social effects, like isolation.

### *Application to endometriosis*

The search yielded two clinical practice guidelines<sup>10,11</sup> and two expert consensus statements<sup>12,36</sup> provided as 'useful clinical guidance' by The Royal Australian and New Zealand College of Obstetricians and Gynaecologists.

The key themes were compared with descriptions of endometriosis in clinical practice guidelines, consensus statements and peer-reviewed literature to determine whether endometriosis meets the definition for chronic disease (Table 2).

Endometriosis met five of the six key themes of chronic disease: causation, duration, treatment, disease course and impact. In terms of causation, endometriosis aetiology is thought to be multifactorial,<sup>11,36</sup> although it is still poorly understood. Endometriosis is a long-term and persistent illness, requiring ongoing management because there is currently no cure,<sup>11</sup> which is consistent with the duration and treatment themes for chronic disease. The impact of endometriosis can be significant, particularly in relation to a woman's work, family and social life, due to the varying symptoms that she may experience. Due to a lack of information regarding the onset of endometriosis in the literature, it was difficult to determine whether endometriosis addresses this key theme.

### **Discussion**

This study identified key themes among chronic disease definitions in Australia and established that endometriosis meets the criteria for chronic disease in this context. The study was robust in using rigorous and replicable processes of document and thematic analyses. Nevertheless, we acknowledge the limitation that the use of documents as an information source in case studies of this type introduces potential bias in that only documents that were publicly available can be considered.<sup>19</sup> To minimise this potential limitation and to capture a wider array of documents, other sources of information provided as references or links were scrutinised in order to obtain additional definitions of chronic disease.

The chronic disease document analysis highlighted that chronic disease is a broad term covering diverse health conditions.<sup>23,31</sup> Overall, however, there are consistencies and the thematic analysis identified six definitional characteristics of chronic disease pertaining to onset, causation, duration, treatment, disease course and impact. The application of these themes to endometriosis identified that it shares five of the six key hallmarks of chronic disease. There is difficulty, based on the available literature, to assess whether endometriosis supports the theme associated with onset. It is acknowledged in the literature that some women present with symptoms in their teens, whereas for other women the symptoms associated with endometriosis may develop in later life.<sup>11,37,40</sup> In addition, some women are asymptomatic, yet have been diagnosed with endometriosis at the time of laparoscopy.<sup>10,11</sup> Despite meeting most of the chronic disease criteria, only one clinical guideline available for use in Australia labelled endometriosis as a chronic disorder.<sup>11</sup>

**Table 2. Thematic analysis of chronic disease characteristics and application to endometriosis**

Theme	Definitions of chronic disease	Application to endometriosis
Onset	<p>Onset varies: it may be gradual<sup>23,25,35</sup> or insidious,<sup>21</sup> sudden or have acute phases<sup>21,35</sup></p> <p>Typically involves a long latency period<sup>22–24,26,34</sup></p> <p>Can occur at any age,<sup>20,21</sup> although some may be more prevalent with older age<sup>20,35</sup></p>	<p>Endometriosis typically affects women of reproductive age<sup>12,36</sup></p> <p>Some women develop symptoms in their teens,<sup>36,37</sup> whereas for others symptoms develop later in life<sup>11</sup></p>
Causation	<p>Characterised by complex causality<sup>20–26,34,35</sup></p> <p>May be associated with multiple risk factors<sup>21–27,30,33,35</sup></p> <p>At times there may be uncertainty around the cause and progression of the disease<sup>26</sup></p> <p>There is variability in terms of causation of the condition among this group of diseases<sup>30</sup></p>	<p>The underlying cause of endometriosis is uncertain<sup>11,36</sup></p> <p>Endometriosis is thought to be multifactorial<sup>36</sup></p>
Duration	<p>Described as a prolonged illness<sup>21–24,26,27,30,34</sup> or long-term condition<sup>20,21,27,31,33,35</sup></p> <p>Persistent illness that continues over time<sup>21–23,25,27,31,33,35</sup></p> <p>Condition present (or expected to be present) for longer than 6 months<sup>3,4,21,28,29,32</sup></p> <p>Condition may be continuous or intermittent<sup>21</sup></p>	<p>Endometriosis requires ongoing management because there is no cure<sup>11</sup></p> <p>Endometriosis is described as a chronic, progressive and relapsing condition<sup>11</sup></p> <p>Some women experience symptoms in their teens<sup>36,37</sup></p> <p>Endometriosis can be associated with chronic pelvic pain (defined as pelvic pain lasting for longer than 6 months)<sup>11</sup></p>
Treatment	<p>Requires ongoing management because chronic conditions typically are not cured<sup>27,31</sup></p> <p>Chronic disease management can become intensive<sup>23,25</sup></p>	<p>Endometriosis may require ongoing management across the life course because it is a long-term and incurable disease<sup>11</sup></p> <p>Treatment focuses on alleviating symptoms<sup>10,11</sup></p> <p>Treatment can involve medical and/or surgical interventions<sup>10,11,36</sup></p>
Disease course	<p>Typically do not resolve spontaneously<sup>21,23,25,26,30</sup></p> <p>Are rarely cured<sup>21–23,25,26,30,31,34</sup></p> <p>Some last indefinitely, yet others resolve over time<sup>30</sup></p> <p>May be associated with a range of complications<sup>21,22,25,26</sup> or sometimes associated with the development of other conditions<sup>23</sup></p> <p>May lead to a gradual deterioration in health<sup>20,21,35</sup></p> <p>Often persist throughout an individual's life, but may not be associated with the cause of death<sup>23,25,27,31</sup></p>	<p>Does not resolve spontaneously and has no cure<sup>11</sup></p> <p>Endometriosis may be associated with the following symptoms:<sup>8,10,11,38</sup></p> <ul style="list-style-type: none"> <li>• pain with menstruation (dysmenorrhea), intercourse (dyspareunia), urination (dysuria), defecation (dyschezia) and ovulation</li> <li>• lower back pain</li> <li>• chronic pelvic pain</li> <li>• heavy menstrual bleeding</li> <li>• gastrointestinal symptoms</li> <li>• subfertility or infertility</li> <li>• fatigue</li> </ul> <p>For some women, pain comes in waves and can increase with severity and duration over time<sup>39</sup></p>
Impact	<p>The effects of chronic diseases vary because some may be associated with premature mortality or disability<sup>22,26,30</sup></p> <p>Chronic diseases may not be life threatening,<sup>21</sup> but they can be associated with premature mortality (due to other underlying causes)<sup>20,21,23,35</sup></p> <p>Individual impacts may include:</p> <ul style="list-style-type: none"> <li>• impairments, activity limitations or disability<sup>20–27,34,35</sup></li> <li>• compromised quality of life<sup>20,21,23,25,35</sup></li> <li>• financial (high cost of medical, treatment expenses, lost productivity)<sup>20</sup></li> <li>• loss of independence<sup>20</sup></li> <li>• social (isolation, family impacts)<sup>20</sup></li> </ul> <p>Societal impacts may include:</p> <ul style="list-style-type: none"> <li>• impact on health and welfare services<sup>27</sup></li> <li>• loss of labour productivity<sup>20</sup></li> </ul>	<p>Symptoms vary widely from woman to woman and are not associated with severity of disease<sup>8,11</sup></p> <p>Individual impacts:</p> <ul style="list-style-type: none"> <li>• quality of life<sup>40–42</sup></li> <li>• financial strain (cost of surgical, medical and complementary treatments to manage the condition)<sup>39,43</sup></li> <li>• emotional well-being<sup>44,45</sup></li> <li>• work life (productivity, meeting job requirements, need for flexible or part-time options)<sup>39,43,44,46,47</sup></li> <li>• relationship strain or breakdown<sup>39,47</sup></li> <li>• social life<sup>45,47</sup></li> </ul> <p>Societal impacts</p> <ul style="list-style-type: none"> <li>• estimated to cost Australia \$7.7 billion annually, consisting of \$2.5 billion in direct health care costs and the remainder in productivity losses<sup>48</sup></li> </ul>



Recognising endometriosis as a chronic disease may offer benefits in terms of improving coordination of care and increasing access to services. Using an existing chronic disease management mechanism, such as CDMs, may provide a structure for coordinating multidisciplinary care for women with endometriosis and can provide women with access to five subsidised allied health services per year. The use of these plans would align with recommendations in three of the four included endometriosis clinical practice guidelines or consensus statements, which highlight a need for a multidisciplinary care team.<sup>10,11,36</sup>

CDMs and TCAs have been implemented for patients with diabetes in Australia and found to be associated with improvements in clinical processes, outcomes and perceived quality of care.<sup>5–7</sup> Further research is recommended to evaluate the use of these plans for women with endometriosis, incorporating a cost–benefit analysis and physicians' perspectives on using these plans to manage this condition.

Despite the utility of CDMs, it is acknowledged that there are some limitations with implementing CDMs in Australia. The recent Parliamentary Inquiry into Chronic Disease Prevention and Management in Primary Health Care<sup>49</sup> highlighted that there are still instances of fragmented service between GPs and allied healthcare providers in implementing these plans. In addition, there is no mechanism to differentiate between patients with simple versus complex cases of chronic disease. Finally, it was noted in the inquiry that the funding mechanism associated with CDMs required review. The matters highlighted during the inquiry may be addressed as the government begins to operationalise the new framework for chronic disease management.

Classifying endometriosis as a chronic disease may provide other benefits, such as increased recognition of the disease among healthcare professionals, the general public and women's support networks. Research suggests that the symptoms of endometriosis are often normalised and women's concerns are often dismissed.<sup>46,50</sup> Further, if endometriosis was classified as a chronic disease, this may provide additional funding opportunities through the National Health and Medical Research Council of Australia because many of the research priority areas relate to chronic disease and associated risk factors.<sup>51</sup> Further research is warranted to examine these concepts for chronic disease generally and for endometriosis specifically.

## Conclusion

This study identified key themes from definitions and characteristics of chronic disease from Australian policy and associated documents. These characteristics were then applied to endometriosis informed by endometriosis guidelines, consensus statements and peer-reviewed literature. Endometriosis shared many of the characteristics of chronic disease in relation to its causation, duration, treatment, disease course and impact. Reframing endometriosis as a chronic disease in clinical practice guidelines and using existing chronic disease mechanisms (e.g. CDMs) may support individualised management strategies for women with endometriosis. The use of these plans may assist with coordination of multidisciplinary care, which could contribute to better health outcomes among women with endometriosis.

## Competing interests

The authors declare no conflicts of interest.

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