

The Impact of Surgically Diagnosed Endometriosis on  
Family and Friend Relationships and Social Engagement

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### Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any University, and, to the best of my knowledge, this thesis contains no material previously published except where due reference is made. I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digital thesis repository, the Library Search and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

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October, 2020

### Contribution Statement

The data analysed in this thesis were collected by Melody Mastrangelo in 2019. Mastrangelo collaborated with her supervisor to select the measures used and to generate and disseminate the survey.

In writing this thesis my supervisor and I collaborated to generate the research aims and hypotheses of interest, and to design the appropriate methodology. I conducted the literature search and completed the ethics application. My supervisor and I created the coding guidelines for the content analysis together. I then completed the content analysis and generated the figures and tables. My supervisor and I sought advice from the University of Adelaide Faculty of Health and Medical Science regarding the statistical analysis. I was then responsible for conducting the analysis on SPSS®. I wrote up all aspects of the thesis.

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## Abstract

*Keywords:* Endometriosis, Social Relationships, Mixed Methods, Content Analysis

Endometriosis is a chronic condition that affects at least 10% of women of reproductive age. Symptoms can include pelvic pain, dysmenorrhea, dyspareunia, bladder and/or bowel problems, and infertility. Nearly 95% of women with endometriosis live with at least one comorbid illness, including depression or anxiety. These factors can have a profound impact on a woman's ability to participate socially. The social impact of endometriosis has been largely under-examined by researchers. The current study seeks to explore this gap in knowledge by using a mixed methods approach to examine a number of women's own statements regarding the impact that endometriosis has had on their family and friend relationships and their ability to engage at social events. Inductive content analyses were conducted on short answer questions (n= 993) to create a numerical count of positive, neutral, and negative statements that women made about the impact endometriosis has had on their relationships and engagement at social events. The statements were largely negative (n=2089), with far fewer neutral (n=164) or positive (n=345) responses. From this the Impact Statement Score (ISS) was created, a measure used to quantify the impacts of endometriosis. The relationship between the ISS and the participants' (n=331) demographic, clinical, and endometriosis-specific characteristics were analysed. Standard multiple regression analyses were conducted to determine the influence a number of variables have on the ISS. This analysis of the ways endometriosis impacts on family and friend relationships and engagement at social events will deepen our understanding of the way endometriosis affects women's lives.

# **The Impact of Surgically Diagnosed Endometriosis on Family and Friend Relationships and Social Engagement**

## ***1.1 Endometriosis***

Endometriosis is a highly individualised, chronic condition that researchers estimate affects 5 - 10% of women of reproductive age and 50% of infertile women (As-Sanie et al., 2019; Hailes, 2016; Dunselman et al., 2014; Department of Health, 2018). It commonly presents as endometrium, cells similar to the lining of the uterus, growing outside the uterus, eventually leading to lesions and scarring (Hailes, 2016). These lesions are typically found on the sidewall of the pelvis and the pelvic organs such as the bowels, bladder, diaphragm and ureter (Hickey et al., 2014; Evans & Bush, 2006). There are three types of endometriosis: superficial peritoneal lesions; deep infiltrating lesions; and cysts (Hickey et al., 2014). Common physical symptoms of endometriosis can include chronic pelvic pain; dysmenorrhea; dyspareunia; bladder and/or bowel problems; and infertility (Evans et al., 2007; As-Sanie et al., 2019). Many women with endometriosis also experience at least one comorbid illness either physical, such as chronic fatigue, irritable bowel syndrome or migraines; or psychological, such as anxiety or depression (As-Sanie et al., 2019; Hailes, 2016; Karp et al., 2011; Hickey et al., 2014; Gambadauro et al., 2019). The root cause of endometriosis is not known, but leading theories include genetics and retrograde menstruation (Hickey et al., 2014; Saha et al., 2015; Hailes, 2016). As the majority of endometrial lesions are too thin to be seen on current ultrasound technology, a laparoscopy is currently the only way to confirm a diagnosis of endometriosis (Evans & Bush, 2006; Kennedy et al., 2005; Hickey et al., 2014).

Women often experience diagnostic delays of between 4 and 10 years (Ballard et al., 2006; Dunselman et al., 2014; Ghai et al., 2019; Singh et al., 2019). This delay is thought to

contribute to feelings of frustration and isolation (Jones et al., 2004b). The reasons for this delay are varied. Many women report having difficulty in distinguishing what was a normal or abnormal level of pelvic pain, as their pain had been ‘dismissed’ or ‘normalised’ by themselves, family members, friends, colleagues, and medical professionals (Ballard et al., 2006; Apers et al., 2017). General Practitioners (GPs) may have limited awareness or knowledge about endometriosis and its variety of presentations, leaving them in the dark as to how to help their patients other than referring them to a wide range of specialists to address the multitude of symptoms (Ghai et al., 2019; van der Zanden et al., 2019). There are often considerable wait times and costs associated with seeing these specialists (Surrey et al., 2020). The common prescription of oral contraceptives as a remedy for pelvic pain or irregular periods in adolescents may also contribute to a delayed diagnosis as it may provide relief from symptoms while still allowing growth of the endometriosis, however more research is needed to confirm this (Dunselman et al., 2014).

As endometriosis is a highly individualised condition, it is recommended that post-diagnosis treatment be patient-specific and involve a multidisciplinary team (Hailes, 2016). During the diagnostic laparoscopy, the surgeon will commonly attempt to repair damage and remove lesions (Evans & Bush, 2006; Hailes, 2016; Dunselman et al., 2014). Post-surgery hormonal treatment is used to limit the likelihood of endometriosis returning (Dunselman et al., 2014; Evans & Bush, 2006). As endometriosis is a chronic condition, and there is currently no cure, many patients must deal with ongoing symptoms post-diagnosis and post-surgery. A number of complementary therapies are also recommended to deal with this including: pelvic floor physiotherapy; exercise; acupuncture; massage; counselling; appropriate sleep; and pain medications (Evans & Bush, 2006; Hailes, 2016; Dunselman et al., 2014). Effectiveness of these treatments vary from patient to patient, and more clinical

research is needed (Evans & Bush, 2006; Hailes, 2016; Dunselman et al., 2014). A number of resources highlight the benefit of in-person or online patient self-help/support groups, and family and friend support (Hailes, 2016; Kennedy et al., 2005; Wilson et al., 2020).

In Australia, endometriosis affects over 700,000 people and is estimated to cost over \$7.7 billion annually, with approximately \$2.5 billion being direct healthcare costs and the rest in lost social and economic participation (Department of Health, 2018; Safe Work Australia, 2019). In July 2018, alongside the release of the National Action Plan for Endometriosis, the Minister for Health, the Honourable Greg Hunt, issued an apology to those who had suffered the devastating consequences of endometriosis due to the historical failures of the Australian Parliament and medical systems (Department of Health, 2018). Since the introduction of the National Action Plan for Endometriosis, over \$12.5 million has been allocated for increased awareness and research focusing on diagnosis and treatment options (Department of Health, 2018; The Hon. Greg Hunt MP, Minister for Health, 2020). Whilst progress in these areas will improve the situation for people living with endometriosis, much research is needed to address the impact endometriosis has on social interaction and participation.

## ***1.2 Relationships and Social Engagement***

Social relationships play a critical role in overall human health, particularly mental health, across a lifetime, and the nature of the social interaction can have important health promoting or damaging impacts on an individual (Seeman, 1996; Kutschke et al., 2018). Supportive relationships may improve resilience and provide a buffer against emotional stress, while strained social relationships leads to the reverse (Kutschke et al., 2018). These effects may extend to physical ailments as well, with suggestions that social strain can lead to

poorer physical health and that these effects are stronger than those associated with positive social support (Brooks et al., 2014). In a systematic review of the association between social relationships and depression, Santini, et al, (2015) found that perceived social support played a significant protective role between chronic illness and depression. Adults with high levels of perceived social support experienced less distress and limitation during their day-to-day activities (Santini et al., 2015). It is clear that positive social interaction and relationships can improve physical and mental wellbeing, unfortunately many symptoms of endometriosis can complicate these fundamental relationships.

Whilst social relationships encompass a wide variety of human interactions including work, education, sport, and leisure activities, the current study focused on family and friend interactions and relationships. These relationships are defined as familial bonds; such as mother, father, sister, brother, grandparents, cousins, aunts, or uncles, all of which may or may not share genetic links; romantic partners of any gender at various stages of relationships; and friend relationships.

Researchers have documented the negative impact of endometriosis on women's social lives, with varying levels of severity (Culley et al., 2013; Mastrangelo, 2019; Mellado et al., 2015; Gilmour et al., 2008; Moradi et al., 2014). It has been estimated that between 19 - 48% of women experience these negative impacts (Culley et al., 2013). A significant number of women analysed in Mastrangelo (2019) reported that they were unable to interact socially or attend events due to their physical symptoms, and this had caused a detrimental impact on their relationships (Mastrangelo, 2019). Chronic pain and discomfort seem to be the root causes of the disruption, with women reporting that their pain controls their lives (Gilmour et al., 2008). The painful, unpleasant, and often embarrassing symptoms of

endometriosis such as IBS symptoms, bleeding, fatigue, pain, and migraines, can have an impact on confidence and self-esteem leading to social isolation (Gilmour et al., 2008; Hållstam et al., 2018). Women report choosing to stay home and avoid social events with friends because their symptoms made them feel burdensome and different to others in attendance, or they became jealous of others at the event (Moradi et al., 2014).

The level of understanding exhibited by friends and family seems to play a significant role in the ability of women to comfortably interact with them whilst dealing with endometriosis. Women reported that understanding and support frequently occurred together while a lack of knowledge concerning endometriosis often resulted in a lack of support (Mastrangelo, 2019). This may have a significant impact on the ability of women to positively interact with family and friends and gain the protective benefits from this experience. This lack of understanding about the nature, evolution, symptoms, and treatment of endometriosis may play a large part in the behaviour of patients and friends that eventually leads to social isolation, such as not being invited to future events after being forced to cancel plans (Mellado et al., 2015; Hållstam et al., 2018). An emerging area of study is the effect of online endometriosis social groups. A recent thematic analysis of posted messages and comments on a Malaysian endometriosis Facebook group suggests that these communities can play an important role in rebuilding women's self-esteem after negative endometriosis related experiences and provide a positive, motivating network of new friends and valuable health resources (Wilson et al., 2020).

The most studied relationship affected by endometriosis is that of romantic partner relationships. In the first study to explore relationship satisfaction through a dyadic lens in couples living with endometriosis, Van Niekerk, et al, (2020) highlight that empathic concern

and emotional intimacy, which enhances understanding, communication, and support, is a protective factor for couples (Van Niekerk et al., 2020). A relationship with low levels of empathic concern and emotional intimacy will be less likely to communicate sympathetically or encouragingly, which may foster feelings of rejection and a reduced ability for the partnership to cope with endometriosis (Van Niekerk et al., 2020). Some women also reported perceiving endometriosis as “their own problem” and are unlikely to share their feelings of distress with their partners, thus restricting this important line of social support (Van Niekerk et al., 2020). Relationship breakdowns were commonly reported and attributed to endometriosis (Huntington & Gilmour, 2005; Mastrangelo, 2019). The causes ascribed were varied: an inability to share an active life; financial strain; sexual difficulties; fertility fears; and misunderstanding of the realities of endometriosis (Denny, 2004; Hållstam et al., 2018).

Partner behaviours vary over time and from couple to couple, from overprotective to insensitive to, at best, accepting and supportive (Hållstam et al., 2018). Partners also expressed an interest in being involved in the medical management of endometriosis (Van Niekerk et al., 2020). Some couples report being able to find satisfying alternatives for intimacy, sexual intercourse, and procreation (Hållstam et al., 2018). Despite the strain endometriosis can put on a couple, it can be the greatest source of support and many women report that they could not have coped with the physical and emotional effects of endometriosis without the encouragement of their partner (Denny, 2004).

The most limited literature was the that impact endometriosis had on social relationships concerning immediate family, such as parent or sibling relationships. Considering the possible genetic link in the causation of endometriosis and the possibility



that more than one member of a close or extended family may have the illness, this may provide a rich source of information and social support for women (Saha et al., 2015).

Hållstam, et al, (2018) describe the limitations on family activities and how young children's lives may be affected by their mother's endometriosis symptoms and the guilt this can cause in the mother (Hållstam et al., 2018). Once again, the concept of understanding, or lack thereof, played an important part in women's relationships, with women withdrawing or distancing themselves from unsupportive family members (Mastrangelo, 2019). This was explored in a narrative analysis of adolescents with endometriosis conducted by Plotkin, the participants described two opposite types of relationships with their parents, particularly their mothers. For some, their mothers were their most supportive relationship, acting as an advocate at school and doctor's appointments, and so they found comfort in the care their mothers provided (Plotkin, 2004). For others, these relationships were more complicated, with parents questioning the validity of the participant's pain, which affected other areas of the participant's life (Plotkin, 2004).

Clearly, endometriosis has far reaching effects on all facets of family and friend relationships. The existing body of literature largely focuses on the variety of negative impacts endometriosis has, such as sexual and fertility difficulties, pain levels that limits engagements at events or shared activities, or feeling burdensome (Moradi et al., 2014; Van Niekerk et al., 2020; Denny, 2004; Hållstam et al., 2018). Only a small fraction of the literature highlights the various positive impacts endometriosis has on intimate relationships, such as close mother-daughter bonds and increased romantic or emotional intimacy (Plotkin, 2004; Van Niekerk et al., 2020). Historically, much of the rich and nuanced data investigating the impact of endometriosis on intimate relationships have come from qualitative studies that have been limited to small sample sizes and so generalisability has been limited as a result

(Moradi et al., 2014; Culley et al., 2013). Culley et al, (2013) suggest researchers should utilise mixed methodologies in future research to employ the strengths of both quantitative and qualitative research (Culley et al., 2013). Another limitation of many of these studies, which may explain why negative consequences are highlighted, is the sample pool from which they draw. Many of these studies find their participants at pain clinics or support groups so they are more likely to have long term or more severe cases, thus skewing the data (Culley et al., 2013; Hållstam et al., 2018).

### ***1.3 Pain, Psychological Health and Quality of Life***

Pain is known to be a major predicting factor of lowered Quality of Life (QoL), psychological health, physical functioning, and emotional wellbeing for women dealing with symptomatic endometriosis (Jones et al., 2004b; Giuliani et al., 2016; Gao et al., 2006; Roomaney & Kagee, 2016; Rush et al., 2019). QoL is a multi-faceted theory concerning an individual's perception of themselves in their own culture in relation to their own expectations, standards, and concerns depending on their physical and psychological health, socio-economic stability, social relationships, and environmental factors (WHOQOL Group, 1998; Giuliani et al., 2016).

The unpredictability of symptom severity and frequency was highlighted in a previous study as having a small but significant negative correlation with all measured dimensions of subjective wellbeing, including: 'life as a whole'; 'standard of living'; 'achieving in life'; 'personal relationships'; and 'community connectedness' (Rush et al., 2019). However, women with endometriosis describe negative impacts on all domains of QoL including socio-economic stability, occupational functioning, sexual and reproduction performance, energy and vitality, physical ability, social connectedness, and psychological and emotional

wellbeing (Jones et al., 2004a; Roomaney & Kagee, 2016). Just as QoL is an intricate concept, understanding the reasons why women with endometriosis have a lower QoL than the general public is just as difficult and the reasons may change as they deal with the different biopsychosocial impacts of the disease at different stages of their lives (Evans & Bush, 2006; Moradi et al., 2014; Culley et al., 2013).

As well as a reduction in QoL, studies highlight the increased likelihood of women with endometriosis experiencing psychological distress (Sepulcri & Amaral, 2009; Culley et al., 2013; Gambadauro et al., 2019). Statistics on women with endometriosis suffering from anxiety and depression vary, with research suggesting that up to 80% of women suffer some form of depression, ranging from mild to severe cases, and up to 65% have high anxiety levels (Sepulcri & Amaral, 2009). Women with surgically diagnosed endometriosis reported significantly higher mean scores on the Depression, Anxiety, Stress Scale-42 (DASS-42) when compared to a normative sample score of the general adult population, 44.84 and 8.3 respectively (Mastrangelo, 2019). Again, pain was a reoccurring factor that contributed to women's anxiety and depression as it left them unable to participate in self-care activities or get good quality sleep, which left them feeling depressed, moody, and angry (Culley et al., 2013; Gambadauro et al., 2019).

A common criticism of studies examining the reduced QoL and increased levels of psychological distress amongst women with endometriosis was that many used generic measures of QoL rather than tools designed to address the nuances of endometriosis (Culley et al., 2013; Arcoverde et al., 2019; Jia et al., 2012). This suggestion prompted the inclusion of the Endometriosis Health Profile – 5 (EHP-5) as part the current study.

### ***1.4 The Current Study***

Despite growing interest in the diagnosis and treatment of endometriosis in recent years, more work must be done in order to understand the impact this disease has on women's relationships. Existing literature supports the notion that symptomatic endometriosis causes an array of impacts on women's family and friend relationships and engagement at social events (Ballard et al., 2006; Culley et al., 2013; Gilmour et al., 2008; Mastrangelo, 2019; Mellado et al., 2015; Moradi et al., 2014; Plotkin, 2004; Van Niekerk et al., 2020). The current study sought to add to this growing body of literature, by focusing on the spectrum of experiences and attempting to quantify the impact of symptomatic endometriosis on women's family and friend relationships and engagement at social events. The current study, to the best of the author's knowledge, was the first study that attempted to quantify this impact into a numerical form, which allowed women's experiences to be directly compared to each other. It was hoped that this mixed method design would provide a rudimentary understanding of the variables that contribute to the impact of endometriosis. This may provide opportunities for future research to build on these findings.

The current study is designed to address a number of methodological issues raised by previous researchers such as: small sample sizes; recruiting participants from pain clinics that may differ from the wider endometriosis population; and use of generic instruments to measure QoL, Health Related QoL (HRQoL), or other relevant information (Culley et al., 2013; Arcoverde et al., 2019; Jia et al., 2012; Moradi et al., 2014). To do this the current study has a sample size over 300, uses an endometriosis specific HRQoL measure, and employed diverse recruiting practices such as social media, radio publicity, as well as the traditional enquiries at women's health clinics.

### ***1.5 Aims and Hypotheses of the Current Study***

The current study had three main aims. The First Aim was to determine what kind of impact endometriosis may have on participants' relationships with their family and friends and engagement at social events. A collective reading of the above-mentioned literature suggested that a spectrum of impact experience may exist. This theory provided the motivation to identify and quantify this impact experience into the newly created Impact Statement Score (ISS). After the completion of the First Aim, the following aims and hypotheses were created.

The Second Aim of this study was to explore the relationships between the impact of endometriosis, as measured by the ISS, and participant QoL as assessed by three clinical measures: the World Health Organisation QoL-BREF (WHOQoL-BREF), the DASS-42, and the EHP-5. As women with symptomatic endometriosis often exhibit psychological distress and score poorly on various QoL measures when compared to control populations, it was thought important to explore this correlation (Sepulcri & Amaral, 2009; Culley et al., 2013; Mastrangelo, 2019). Based on this aim, the following five hypotheses were proposed.

Hypothesis one: all domains of the WHOQoL-BREF will have a positive relationship with the ISS.

Hypothesis two: the Social Relationship Domains of the WHOQoL-BREF will have a stronger correlation with the ISS than the Psychological, Physical or Environmental Domains.

Hypothesis three: the three sections of the DASS-42 will be negatively correlated with the ISS.

Hypothesis four: depression, as measured by the DASS-42, will have a stronger correlation with the ISS than either Anxiety or Stress.

Hypothesis five: both parts of the EHP-5 will have a negative relationship with the ISS.

Finally, the Third Aim of this study was to examine what influence participants' general and endometriosis specific variables had on the impact of endometriosis on family and friend relationships and engagement at social events. Examples of general variables being hours of sleep, time spent with family and friends, or time spent at work; and examples of endometriosis-specific variables being physical or psychological symptoms, or delay in diagnosis.

## **Method**

### ***2.1 Previous Work***

The data analysed in this research are the unidentified subset of data collected by Mastrangelo. References to Mastrangelo's data collection procedure will be made here. For further information please refer to her thesis, available in the Barr Smith library located at the University of Adelaide North Terrace Campus.

### ***2.2 Participants***

The initial research took a cross-sectional approach to sampling (Mastrangelo, 2019). The eligibility conditions specified that participants must: reside in Australia; be over 18 years of age; have a surgical diagnosis of endometriosis; and be symptomatic (Mastrangelo, 2019). These criteria were selected as it is known that the majority of women with a diagnosis of endometriosis are of reproductive age; currently the only way to confirm endometriosis is by undergoing laparoscopic surgery; and it was presumed women with asymptomatic endometriosis would not experience significant disruptions to their social lives (Evans & Bush, 2006; Hickey et al., 2014; Mastrangelo, 2019). As the survey was conducted online, researchers relied on the participants' self-report to determine participants had

undergone laparoscopic surgery to officially diagnose their endometriosis. A total of 970 eligible participants completed the original online survey (Mastrangelo, 2019).

In order to protect participants' anonymity, and to honour the specific consent granted by participants included in the initial study, the current research only analysed data that has never had any identifying information or contact details attached. A total of 331 participants were included in the current study. Quantitative QoL data and select qualitative data were analysed for all 331 participants. Only 305 participants were included in the final multiple regression model analyses, as these participants had complete data.

### ***2.3 Materials and Measures***

A 25-minute online survey (Appendix A), hosted on SurveyMonkey, was initially distributed on Mastrangelo's social media accounts (Mastrangelo, 2019). An information sheet outlining the purpose of the study, the possible risks or benefits, research team details and contact information, participant privacy information, and survey procedure immediately preceded the start of Mastrangelo's survey (Appendix B). A poster (Appendix C) was displayed within three women's health clinics in Adelaide, South Australia: O and G; Women's Health Specialists; and Aware Women's Health (Mastrangelo, 2019). A modified version of the poster (Appendix D) was shared on Endometriosis Australia's social media to promote the survey (Mastrangelo, 2019). Mastrangelo was contacted by ABC Riverland Radio and subsequently gave an interview on the morning program to discuss the study and encourage listeners to participate (Mastrangelo, 2019). As a result of the media attention and online sharing, a snowball sample was generated (Mastrangelo, 2019). Due to the overwhelming response, the survey was closed earlier than expected (Mastrangelo, 2019).

Upon completion of the survey, participants were given the option to provide their contact details in order to receive a summary of key research findings, or to have their results on the clinical measures (WHOQoL-BREF, EHP-5, and DASS-42) forwarded to their GP. By submitting the survey, participants gave specific consent for their data to be used in Mastrangelo's research.

Three areas of demographic information were gathered: general; endometriosis-specific; and clinical characteristics. General demographic information included: age; marital status; number of children; sexuality; education level; employment status; as well as six quantitative estimated lifestyle questions. Endometriosis-specific demographic information included: age of onset; age of surgical diagnosis; type of surgeries undergone; number of surgeries; and a description of participants' self-identified symptoms (both physical and psychological). Participants' clinical characteristics were obtained from the results of three clinical measurements: DASS-42, EHP-5, and WHOQoL-BREF. Seven open-ended questions were presented to participants in order to examine the impact of surgically diagnosed endometriosis on women's ability to participate socially.

### **2.3.1 World Health Organization Quality of Life – BREF (WHOQoL-BREF; WHOQOL GROUP, 1995)**

This measure is the short form version of the WHOQOL-100, developed for ease of clinical and research use. It is designed to assess an "individual's perception of their situation in life in the context of their culture and value systems, and in relation to their expectations, goals, standards, and concerns" (World Health Organization, 1998). These instruments were developed as part of the WHO's promotion of a holistic approach to health and healthcare,



and to facilitate collaborative quality of life (QoL) research across different cultural settings (WHOQOL GROUP, 1995).

The WHOQOL-BREF is made up of 26 questions, written in plain language, that assess four domains of Quality of Life: Physical health; Psychological; Environment; and Social Relationships (World Health Organization, 1998). Each question measures the response using a five-point Likert scale (World Health Organization, 1996). This instrument is scaled in a positive direction. Participants scores in each of these domains were calculated according to the WHOQoL handbook with the assistance of an WHOQoL Calculator created in excel by Skvarc (2018).

The World Health Organization analysis shows good internal reliability using Cronbach alpha: Physical health = .82; Psychological = .75; Environment = .80; and Social Relationships = .66 (World Health Organization, 1998). It should be noted that only three questions are contained in the Social Relationships domain, so Cronbach alphas may be unreliable (World Health Organization, 1998).

### **2.3.2 Endometriosis Health Profile-5 (EHP-5; Jones et al., 2004)**

The Endometriosis Health Profile-5 (EHP-5) is a patient-generated, disease-specific, health-related QoL (HRQoL), self-report questionnaire designed to measure the health impacts of endometriosis (Jones et al., 2001; Jones et al., 2004a). It has been abbreviated from the longer form EHP-30 for ease of clinical and research use and to mitigate possible effects on the data by the larger scale data collection methods (Jones et al., 2004a).

It is separated into two sections, the 'core' and the 'modular'. The core section includes five items examining a domain each: Pain; Control and Powerlessness; Emotions; Social Support; and Self Image (Jones et al., 2004a). The modular section, made up of six items measuring a domain each, can be modified from study to study depending on the particular aims of the research (Jones et al., 2004a). The current study used the modular section to examine: Work Life; Relation with Children; Sexual Intercourse; Medical Profession; Treatment and Infertility (Jones et al., 2001; Jones et al., 2004a). Responses are measured on a five-point Likert scale from 'never' to 'always', and an additional response of 'not relevant' is also available for the modular section (Jones et al., 2001; Jones et al., 2004a). A low score indicates a positive health status while a high score indicates a negative health status. The EHP-5 is known to have high internal consistency (Fauconnier et al., 2017).

### **2.3.3 Depression Anxiety Stress Scale -42** (DASS-42; Lovibond & Lovibond)

This 42-item self-report measure is designed to analyse three negative emotional states: Depression, Anxiety, and Stress (Lovibond & Lovibond, 1995). The DASS-42 has been identified as having good internal consistency and providing a superior separation of emotional states compared to other existing measures (Antony et al., 1998). Each item measures the response on a four-point scale, gauging the frequency that the respondent felt they experienced certain negative thoughts or feelings over the past week (Lovibond & Lovibond, 1995). The Cronbach alpha values for each domain examined by Antony et al, (1998) show strong internal reliability: Depression = .97, Anxiety = .92, and Stress = .95 (Antony et al., 1998).

### **2.3.4 Open-ended Survey Questions**

Three open-ended questions were selected from Mastrangelo's original seven questions. These questions were selected in order to focus exclusively on family and friend relationships and engagement at social events. Questions were phrased to participants as 'How has your experience with endometriosis impacted... (Q1) on your social interaction with your family; (Q2) on your social interaction with friendships and relationships with friends; (Q3) upon your attendance and engagement at social events?' Participants were able to write as much or as little as they wanted in response to the questions (Mastrangelo, 2019). Participants were encouraged to be as open and detailed as possible (Mastrangelo, 2019). Responses to these questions were called *Impact Statements*.

### **2.3.5 Estimated Lifestyle Questions**

The following six questions were designed to measure participants' estimated time spent engaged in particular activities per week in discrete ranges: 0 hours, 1 hour or less, 1-3 hours, 4-6 hours, 7-9 hours, 10+ hours. Questions were posed to participants as 'Approximately how many hours ... (Q1) of paid work do you do; (Q2) do you sleep per night; (Q3) do you spend with your friends or family; (Q4) do you spend at social events; (Q5) do you engage in leisurely activities; (Q6) do you spend doing household tasks?' These questions were included in order to compare the level of social participation (Q3-Q5) and everyday functioning (Q1, Q2 and Q6) between the participants (Mastrangelo, 2019).

## ***2.4 Analysis***

Content analysis procedure was used to examine the 993 open-ended survey responses, 331 responses per each of the three open ended questions, in Excel (Mayring,

2000). Due to the limited amount of literature concerning the impact of endometriosis on family and friend relationships and engagement at social events, an inductive approach was used throughout the analysis. This approach allows for the emergence of new concepts, models, categories, or theories from the data where little is known about the experience (Thomas, 2003, Elo & Kyngäs, 2008).

A set of guidelines (Appendix E), with which to identify and code participants' Impact Statements, were established to conduct the content analysis. These guidelines were developed with Professor Turnbull using an iterative process of independent and interdependent coding to check validity and reliability of the codes. Participants' Impact Statements were coded into three categories: Positive, indicating endometriosis has had a good impact on Family and Friend relationships and engagement at social events; Negative, indicating endometriosis has had a bad impact on Family and Friend relationships and engagement at social events; and Neutral, indicating endometriosis had no significant impact on Family and Friend relationships or engagement at social events. This method allowed the quantifying of the qualitative Impact Statements and the assigning of a numerical value to the Impact Statements. These Positive, Neutral and Negative Impact Statement values were then used to create the Impact Statement Score (ISS). The ISS is calculated using the formula:

$$ISS = \text{Positive Statements} + (\text{Neutral Statements} \times 0.5) - \text{Negative Statements}$$

This formula was designed to simply explain the impact as all three impact types were often present in a participant's statements. A positive score is achieved when the positive statements and half of the neutral statements identified outweigh the total number of negative statements identified in the participant's responses. This positive score indicates that

endometriosis has had a good overall impact on Family and Friend relationships and engagement at social events in the participant's life. A negative score is achieved when the negative statements identified outweigh the total number of positive statements and half of the neutral statements identified in the participant's responses. This negative score indicates that endometriosis has had a bad overall impact on Family and Friend relationships and engagement at social events in the participant's life. A neutral score is achieved when the positive statements and half of the neutral statements identified are equal to the total number of negative statements identified in the participant's responses. This score indicates that endometriosis has had no significant overall impact on Family and Friend relationships or engagement at social events in the participant's life.

A second content analysis was conducted on a randomly selected 20% of participants to assess the overlap of content areas, such as loss of contact with friends or lack of understanding from family, between the three open-ended survey questions. Only 20% of participants were included in this analysis due to time restraints. Analysis was conducted in NVivo® 12. This was conducted to validate analysing all three questions together rather than separately.

General and endometriosis-specific demographic information was examined in Excel to provide a description of the sample. Participants' results on all three clinical measures, WHOQoL-BREF, EHP-5, and DASS-42, were calculated in Excel and analysed using SPSS Statistics® 26. Correlations (Spearman's  $r_s$  was used as data was deemed non-normally distributed) were run between the ISS and each domain of the three clinical measures, and the ISS and demographic variables, including endometriosis-specific information and estimated

lifestyle questions, to investigate the relationships. Multiple regression modelling was conducted using SPSS' 'Enter' method.

## ***2.5 Ethics***

Ethics approval for the initial study was granted by The University of Adelaide Human Research Ethics Committee (HREC), approval #H-2019-097 (Appendix F). A consent waiver was granted by The University of Adelaide HREC, approval #H-2020-111 (Appendix G), for use of the unidentified subset of the data collected by Mastrangelo. Only the data belonging to the participants who elected to remain anonymous and did not wish to receive any follow up information were used in the current study.

## **Results**

### ***3.1 Data Screening***

Before analysis, data were screened for incomplete profiles and invalid responses or values. A total of 331 participants were included in the content analysis. Due to missing values, only 305 participants were included in the final multiple regression modelling.

Prior to analysis all the clinical measures, WHOQoL-BREF, DASS-42, and EHP-5 were screened for normality. Histograms and Q-Q plots were visually assessed, however no confident conclusion on normality could be drawn from this visual assessment (Yap & Sim, 2011; Ghasemi & Zahediasl, 2012). Each measure's skewness and kurtosis values were calculated and, as the sample was >200 the range was set to  $\pm 2.58$  with  $\alpha = .01$  (Ghasemi & Zahediasl, 2012; Laerd Statistics, 2015). Very few measures were within this range. Finally, the Shapiro-Wilk(S-W) test returned non-normative results for all measures. While

commonly used for sample sizes <50, S-W has shown to be robust on samples ranging from 3 to 5000 (Yap & Sim, 2011; Mohd Razali & Bee Wah, 2011, Laerd Statistics, 2018).

### ***3.2 Characteristics of Participants***

The participants' general and endometriosis-specific demographic information are outlined in Table 1 and Table 2 respectively. The women were aged between 18 and 51 years, with a mean age of 28.4 years (SD=6.9). The majority of the women were in some form of relationship and identified as heterosexual. Three quarters of the women did not have children. Almost 80% of women were active in the workforce, either full-time, part-time, or casual. Only 27.5% of the women were attending some form of education including University, Technical and Further Education (TAFE), or other institutions.

**Table 1**

*Demographic Characteristics of Participants*

Characteristics	<i>n</i>	%
Country of Birth		
Australia	304	91.8
New Zealand	6	1.8
England	8	2.4
Other	13	3.9
Marital Status		
Single	77	23.3
In a Relationship	136	41.1
Married	112	33.8
Separated but not Divorced	3	0.9
Divorced	3	0.9
Sexuality		
Prefer not to say	9	2.7
Bisexual	38	11.5
Homosexual	4	1.2
Heterosexual	280	84.6

Number of Children		
0	251	75.8
1	40	12.1
2	27	8.2
3+	13	3.9
Currently Studying		
Studying Full Time	59	17.8
Studying Part Time	32	9.7
Not Studying	240	72.5
Employment Status		
Full-time Employment	128	38.7
Part-time Employment	67	20.2
Casual Employment	67	20.2
Unemployed	44	13.3
On leave	19	5.7
Other Work (Paid or Unpaid)	6	1.8

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*Note.*  $N = 331$ . Participants were on average 28.4 years old ( $SD=6.9$ ).

Most women received a surgical diagnosis either between the ages of 18-24 (44.7%) or 35-44 (31.7%). The majority of women reported experiencing symptoms before the age of 18. Almost a third of women reported a 9+ year delay between the onset of their symptoms and receiving a surgical diagnosis. The majority of women described 4-6 physical symptoms and 1-2 psychological symptoms.

Table 3 provides a breakdown of the participants' activities. The majority of women spent 1-3 hours with their family and friends per week. A similar number of women reported spending either 1 hour or less (35%), or 1-3 hours (31.1%) a week at social events. Most women spent 1-3 hours a week doing general household tasks. A third of women were unable to participate in any leisure activities. Almost 10% of women were only getting four hours of sleep or less per night.



**Table 2***Endometriosis-Specific Demographics of Participants*

Endometriosis-Specific Characteristics	<i>n</i>	%
<b>Age of Symptom Onset</b>		
Under 18	215	65.0
18-24	60	18.1
25-34	25	7.6
35-44	6	1.8
45-54	1	0.3
Not Answered	24	7.3
<b>Age of Surgical Diagnosis</b>		
Under 18	31	9.4
18-24	148	44.7
25-34	105	31.7
35-44	20	6.0
45-54	3	0.9
Not Answered	24	7.3
<b>Years between Onset &amp; Diagnosis</b>		
0-2	74	22.4
3-4	51	15.4
5-6	46	13.9
7-8	35	10.6
9+	101	30.5
Not Answered	24	7.3
<b>Self-Identified* Physical Symptoms</b>		
0	2	0.6
1-3	112	33.8
4-6	113	34.1
7-9	53	16.0
10-12	18	5.4
13-15	3	0.9
16-20	4	1.2
Not Answered	26	7.9
<b>Self-Identified* Psychological Symptoms</b>		
0	112	33.8
1-2	161	48.6
3-4	27	8.2
5-6	4	1.2
7	1	0.3
Not Answered	26	7.9

*Note.* *N* = 331. \*Women were given space to list their symptoms. A content analysis was then conducted to quantify these brief lists/statements.

**Table 3***Estimated Lifestyle Demographics of Participants*

Estimated Lifestyle Demographics	<i>n</i>	%
Hours of Sleep per night		
4 or less	32	9.7
5-6	131	39.6
7-8	147	44.4
9+	21	6.3
Hours spent with Family & Friends per week (e.g. gatherings, parties, lunches, etc.)		
0	22	6.6
1 or less	67	20.2
1-3	134	40.5
4-6	76	23.0
7-9	16	4.8
10+	16	4.8
Hours spent at Social Events per week (e.g. gatherings, parties, lunches, etc.)		
0	82	24.8
1 or less	116	35.0
1-3	103	31.1
4-6	26	7.9
7-9	3	0.9
10+	1	0.3
Hours spent at Leisure Activities per week (e.g. netball, hiking, swimming, etc.)		
0	110	33.2
1 or less	82	24.8
1-3	99	29.9
4-6	34	10.3
7-9	4	1.2
10+	2	0.6
Hours spent doing General Household Tasks per week (e.g. cleaning, gardening, cooking, grocery shopping, etc.)		
0	1	0.3
1 or less	48	14.5
1-3	152	45.9
4-6	77	23.3
7-9	27	8.2
10+	26	7.9

*Note.* *N* = 331.

### ***3.3 Aim One: Determine if Endometriosis has an impact on Family and Friend Relationships and Engagements at Social Events***

The content analysis identified three types of impact: Positive; Neutral; and Negative. Examples of participants' responses are given in Table 4. The majority of the statements were found to be negative, indicating that endometriosis had caused women's relationships with family and friends and engagement at social events to worsen. There were many more positive responses identified in the responses concerning family and friends than engagement in social events. Impact breakdowns can be found in Figures 1, 2, 3.

**Table 4**

*Examples of Positive, Neutral, and Negative quotes identified during content analysis*

Code	Question...	Direct Quote Example
Positive	1	"My family are incredibly supportive."
	1	"My immediate family paid for my laparoscopy."
	1	"My endometriosis has actually strengthened my relationship with my mother."
	2	"Friends are very supportive made my friendships stronger with people that understand and try to hrlp[sic]."
	2	"My friends are extremely supportive and understanding. The offer to do my groceries, cook for me, run errands or entertain my daughter for me."
	2	"I have great friends who ... come and just hang out around the house if that's what I needed them to do."
	3	" I've still been able to go out with friends..."
	3	"Most people are very understanding [when I need to cancel]."
Neutral	1	"It hasn't particularly impacted my relationship with family."
	1	"I try not to let it beat me."
	2	"Not really told them."
	2	"I don't see a major negative on my friendships."
	3	"No Impact."
	3	"I don't think it has ..."
Negative	1	"My family relationships are sometimes strained . . ."

- 1 "It was hard explaining the cause of my infertility to them. They were either squeamish or didn't want to know."
- 2 "Female friends couldn't grasp how much pain I was in, thought I was overreacting..."
- 2 "My partner and I have difficulty with our sex life. . ."
- 2 "It limits my ability to be social."
- 2 "I no longer have any friends."
- 3 "Has resulted in stopping attendance at some social engagement."
- 3 "...if I make it out I'm not the life of the party and people notice and wonder why I even both[er]."
- 3 "Big impact i don't[sic] feel like leaving the house."

*Note.*

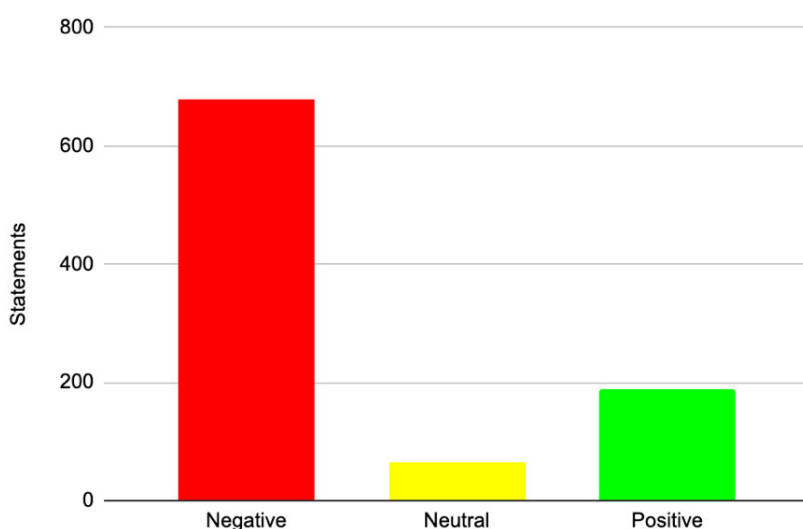
Question 1 = How has your experience with endometriosis impacted on your social interaction with your family (immediate and extended)?

Question 2 = How has your experience with endometriosis impacted on your social interaction with friendships and relationships with friends?

Question 3 = How has your experience with endometriosis impacted on your attendance and engagement at social events (e.g. gatherings, parties, lunches etc)?

**Figure 1**

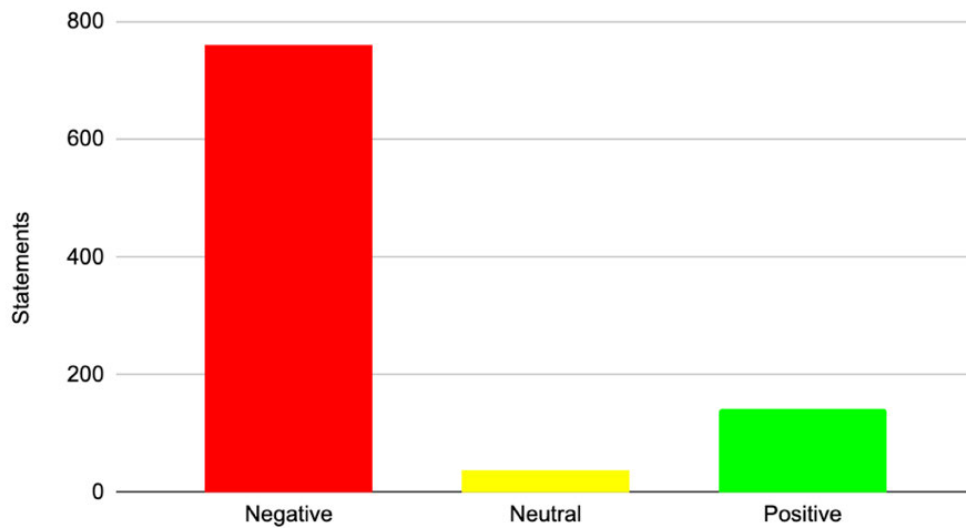
*Content Analysis of Question One: How has endometriosis impacted on your social interaction with your family (immediate and extended)?*



*Note.* Coding of statements ( $n=331$ ) for Question 1. Negative = 679, Neutral = 66, Positive = 189.

**Figure 2**

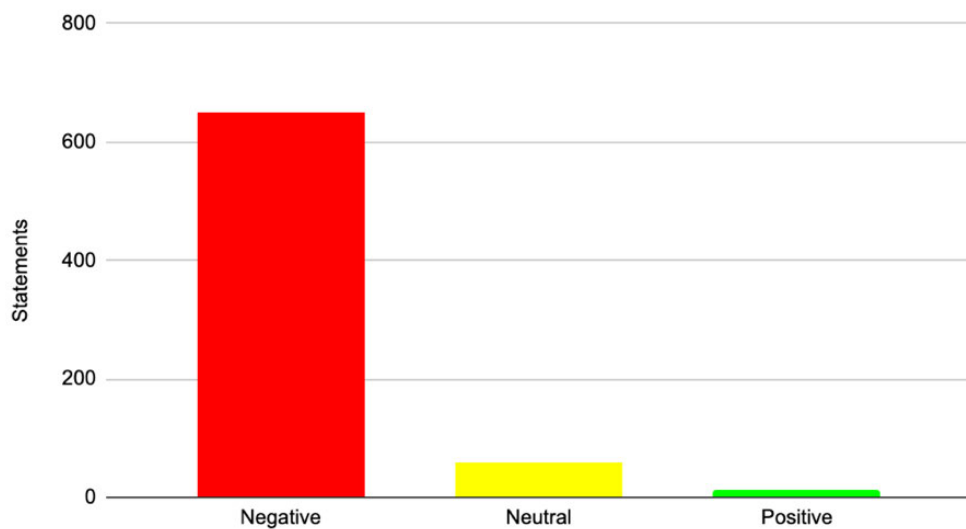
*Content Analysis of Question Two: How has endometriosis impacted on your social interaction with friendships and relationships with friends?*



*Note.* Coding of statements ( $n=331$ ) for Question 2. Negative = 760, Neutral = 38, Positive = 142.

**Figure 3**

*Content Analysis of Question Three: How has endometriosis impacted on your attendance and engagement at social events (e.g. gatherings, parties, lunches, etc.)?*



*Note.* Coding of statements ( $n=331$ ) for Question 1. Negative = 650, Neutral = 60, Positive = 14.

The second content analysis revealed seven *content areas*, summarised in Table 5. Participants reported either a lack of understanding resulting in a negative outcome or positive support from understanding (content area 1). Many participants had lost contact (content area 2) or cut ties with family members or friends because of endometriosis. Participants highlighted having to leave an event abruptly or cancelling last minute (content area 3). A small number of participants conveyed frustration at being left out of activities due to difficulties with food or drink (content area 4), particularly alcohol. Some participants revealed difficulty being around or discussing pregnancy, babies or children (content area 5). Participants also expressed their reliance on their medication or treatment (content area 6). A large number of participants stressed the impact that their symptoms (content area 7) had on their participation with family, friends, and at social events.

As a result of this content analysis the decision was made to analyse the responses to the Impact Statements from each of the three questions together as one response, this is summarised in Figure 4. Participants were then ranked according to their ISS. This is visualised in Figure 5. The vast majority of participants scored a negative impact, with only 9.7% of participants ranking as positive and 2.7% of participants scoring 0. The ISS facilitated comparisons between participants by quantifying the impact endometriosis has had on the participant's relationships with their family and friends and engagement at social events. Using the procedure outlined in the data screening section, the ISS was found to be non-normally distributed.

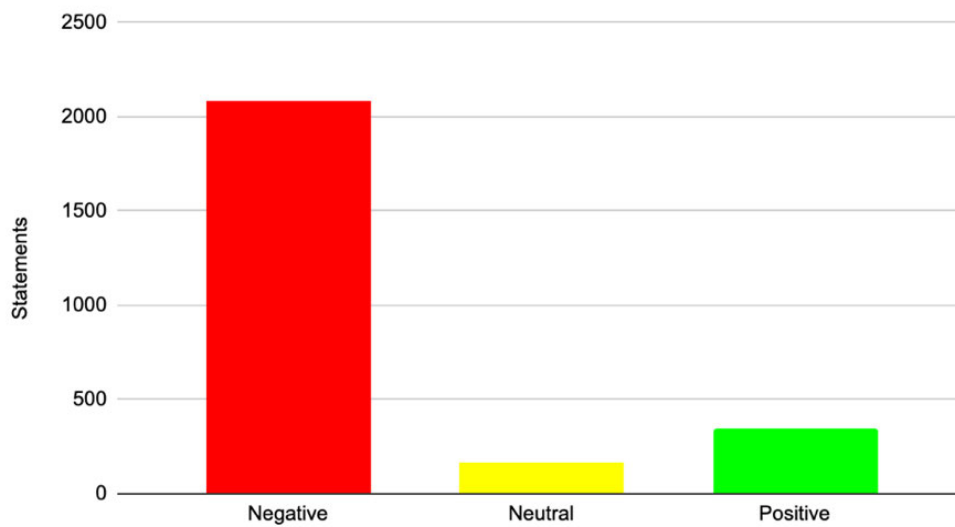
**Table 5***Content analysis of similar Content Areas across all three questions*

Code	Content Area	Statements Identified			Direct Quote Example
		Q1	Q2	Q3	
1	Others Comprehension	31	22	7	"Family and friends don't fully understand..."
2	Loss of Contact	12	15	2	"I have lost a lot of people..."
3	Interruption of Plans or Events	17	24	39	"I leave most events early or avoid them all together."
4	Difficulty with Food or Drink	1	3	9	"I am now on [a] pretty specific diet. Can make it difficult when I eat out with others."
5	Avoiding Pregnancy & Children	7	8	3	"Can't handle being around pregnant woman, and other bab[ies] or children. Avoid place where children are."
6	Medication or Treatment	6	1	7	"I'll be lying in bed with a heat pack counting down the minutes til I can take the next naprogesic tablet."
7	Symptoms	50	49	63	"I don't even want to talk to anyone when the pai[n] kicks in."

*Note.* N=198. 66 responses from each of the three questions. *Statements Identified* are the number of times an individual statement fragment expressing the content area being counted was expressed within each survey question.

**Figure 4**

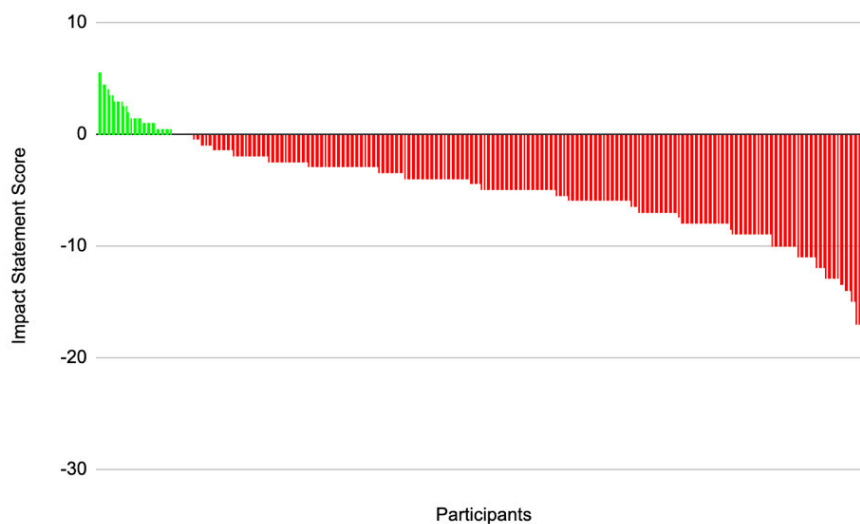
*Content Analysis of the Questions Combined.*



*Note.* Coding of statements ( $n=993$ ) for all questions. Negative = 2089, Neutral = 164, Positive = 345.

**Figure 5**

*Participants Impact Statement Score.*



*Note.* Participants ( $n=331$ ), *Formula* = Positive Score+(Neutral Score x 0.5)- Negative. The average score = -5 (SD=4.3), Minimum= -21, Maximum= 5.5.



### ***3.4 Aim Two: Determine if there is a Correlation between the Impact of Endometriosis and Participants' Clinical Characteristics***

Aim Two sought to explore the relationship between the impact of endometriosis and the clinical characteristics of the participants. To do this, correlations were run between the ISS and each of the clinical measures: WHOQoL-BREF; DASS-42; and EHP-5. As the data were non-normally distributed, Spearman's correlation was used. The analysis was set as two-tailed with  $\alpha=.05$ . These correlations are summarised in Table 6 below.

Hypothesis one predicted that all domains of the WHOQoL-BREF would have statistically significant, positive relationships with the ISS, and hypothesis two predicted that the Social Relationship Domain would have a stronger correlation than the Psychological, Physical, or Environmental Domains. Results demonstrated that there was a statistically significant, weak positive correlation between the ISS and each domain of the WHOQoL-BREF. Contrary to prediction, the Social Relationship Domain ( $r_s(329)=.33, p<.01$ ) did not have stronger correlations with the ISS than the Psychological ( $r_s(329)=.33, p<.01$ ), Physical ( $r_s(329)=.33, p<.01$ ), or Environment ( $r_s(329)=.29, p<.01$ ) Domains.

Hypothesis three predicted the three sections of the DASS-42 and the ISS would have a statistically significant, negative relationship. Hypothesis four predicted depression would have a stronger correlation with the ISS than either anxiety or stress. Findings reveal there were indeed statistically significant, weak negative correlations between the ISS and each section of the DASS-42. The expectation that depression ( $r_s(329)=-.31, p<.01$ ) would have a stronger relationship with the ISS than anxiety ( $r_s(329)=-.22, p<.01$ ) or stress ( $r_s(329)=-.21, p<.01$ ) was supported.

Hypothesis five predicted there would be a statistically significant, negative relationship between both parts of the EHP-5 and the ISS. Analysis shows this hypothesis was supported and there was little difference in the relationship between the ISS and the EHP-5 Core ( $r_s(329)=-.36, p<.01$ ) section or Modular ( $r_s(329)=-.32, p<.01$ ) section.

These findings show that there is a relationship between the impact of endometriosis on family and friend relationships and engagement at social events, and participants' clinical characteristics.

**Table 6**

*Correlation matrix assessing the relationship between the Impact Statement Score and various scales.*

Scale	Impact Statement Score
WHOQoL-BREF	
Physical Domain	0.33**
Psychological Domain	0.33**
Social Relationship Domain	0.33**
Environment Domain	0.29**
DASS	
Depression	-0.31**
Anxiety	-0.22**
Stress	-0.21**
EHP-5	
Core	-0.36**
Modular	-0.32**

*Note.* N=331, DF=329. As all data are non-normally distributed Spearman's Correlation was used.

\*\*  $p < 0.01$

### ***3.5 Aim Three: What influence do the General and Endometriosis-Specific Demographic Variables have on Impact***

Aim Three was to determine which general and endometriosis-specific variables were predictive of the ISS, and the extent of their predictive value. In order to assess this using a standard multiple regression, a number of independent variables were selected: Years between Onset & Diagnosis, Time with Family & Friends, and Time Spent at Social Events, amount of Sleep, Physical symptoms, and Psychological symptoms. These six variables were selected due to their analysis in previous literature (Ballard et al., 2006; Apers et al., 2017; Seeman, 1996; Kutschke et al., 2018, Brooks et al., 2014, Santini et al., 2015, Moradi et al., 2014, Mellado et al., 2015; Hållstam et al., 2018, Saha et al., 2015; Culley et al., 2013; Gambadauro et al., 2019; Gilmour et al., 2008; Hållstam et al., 2018, Rush et al., 2019, Sepulcri & Amaral, 2009).

The independent variables were screened for normality using the process outlined in the data screening section. They were determined to be non-normally distributed. Before the standard multiple regression could be run, correlations were used to establish if there was a relationship between the ISS and each of the independent variables. Spearman's correlation, with the same setting as previously stated, are used. These correlations are summarised in Table 7.

**Table 7**

*Correlation matrix assessing the relationship between the Impact Statement Score and Independent Variables.*

Independent Variables	Impact Statement Score
Time with Family & Friends (hrs per week)	0.15**
Social Events (hrs per week)	0.12*
Hours of Sleep (per night)	0.17**
Physical Symptoms <i>n</i> =305, <i>DF</i> =303	-0.33**
Psychological Symptoms <i>n</i> =305, <i>DF</i> =303	-0.30**
Years between Onset & Diagnosis <i>n</i> =307, <i>DF</i> =305	-0.08

*Note.* *N*=331, *DF*=329 unless otherwise specified. As all data is non-normally distributed, Spearman's Correlation was used.

\*\**p* = <0.01

\**p* = <0.05

Contrary to expectations there was no statistically significant relationship between the ISS and Years between Onset & Diagnosis. It was removed as an independent variable from the standard multiple regression.

A standard multiple regression model (Model 1) was conducted with ISS as the dependent variable. The five independent variables were: Time with Family & Friends; Time Spent at Social Events, amount of Sleep; Physical symptoms; and Psychological symptoms. It was hypothesised that these independent variables would account for a statistically significant proportion of the variance in the ISS. Test assumptions were assessed in line with the Laerd Statistics Multiple regression guide (2015) and advice outlined by Ernst and Albers (2017).

Linearity was visually established between ISS and each of the variables by partial regression plots. Linearity of the model was not supported by a visual inspection of a plot of the studentized residuals against the predicted values, violating an assumption of the test. There was independence of residuals, as assessed by a Durbin-Watson statistic of 2.190. The model violates the assumption of homoscedasticity, as assessed by visual inspection of the studentized residuals against the predicted values. There was no evidence of multicollinearity, as assessed by tolerance values greater than .1 and variable correlations less than .7. The criteria for outlier detection was set at  $\pm 3$  SD. Two outliers were detected. After confirming there were no data entry issues and no reasonable argument to remove the outliers, it was decided these cases should remain in the data set for analysis. No high leverage points were found in the data and no cases exhibited undue influence according to Cook's distance values (Huber, 1981; Cook & Weisberg, 1982). Visual assessment of the histogram and P-P plot supported the normality of residuals. However, the data appears somewhat peaked.

Results from Model 1 indicated that the five variables did statistically significantly predict the ISS,  $F(5, 299) = 17.632$ ,  $p < .001$ ,  $R^2 = .228$ , Adjusted  $R^2 = .215$ . This model accounts for 21.5% of variation in ISS. Regression coefficients, standard errors, and significance can be found in Table 8. However, the independent variables Time with Family & Friends, and Time Spent at Social Events were found to be non-significant within the model. This indicates they are superfluous to the model and do not account for a meaningful percentage of the variation. Removing them from the modelling and conducting the second model resulted in a 0.8% reduction of variance in the ISS being explained. Model 2 focused on the symptomatic independent variables, physical, psychological, and hours of sleep. This standard multiple regression model statistically significantly predicted Impact Statement

Score,  $F(3, 301) = 27.473$ ,  $p < .001$ ,  $R^2 = .215$ , Adjusted  $R^2 = .207$ . It accounted for 20.7% of variation in the ISS. All variables in Model 2 were statistically significant. Regression coefficients, standard errors and significance can be found in Table 8.

Assumption testing for Model 2 followed the same procedure as Model 1 (Laerd Statistics, 2015; Ernst & Albers, 2017). Linearity was visually established between ISS and each of the variables by partial regression plots. Linearity of the model could not be identified visually by a plot of the studentized residuals against the predicted values, violating an assumption of the test. There was independence of residuals, as assessed by a Durbin-Watson statistic of 2. The model violates the assumption of homoscedasticity, as assessed by visual inspection of the studentized residuals against the predicted values. There was no evidence of multicollinearity, as assessed by tolerance values greater than .1 and variable correlations less than .7. The criteria for outlier detection was set at  $\pm 3$  SD. The same two outliers were detected; however, these were retained for analysis. No high leverage points were found in the data and no cases exhibited undue influence according to Cook's distance values (Huber, 1981; Cook & Weisberg, 1982). Visual assessment of the histogram and P-P plot supported the normality of residuals.

As both standard multiple regression models violated the assumption of homoscedastic and linearity, we cannot have confidence in the results of either of these models (Laerd Statistics, 2015; Ernst & Albers, 2017).

**Table 8***Multiple regression results for Impact Statement Score*

	<i>B</i>	<i>95% CI for B</i>		<i>SE B</i>	$\beta$	$R^2$	$\Delta R^2$
		<i>LL</i>	<i>UL</i>				
Model 1						0.23**	0.22**
Constant	-4.70**	-6.44	-2.95	0.89			
Time with Family & Friends (hours per week)	0.33	-0.11	0.77	0.22	0.09		
Social Events (hours per week)	0.16	-0.36	0.69	0.27	0.04		
Hours of Sleep (per night)	0.68*	0.11	1.25	0.29	0.12*		
Physical Symptoms	-0.38**	-0.52	-0.24	0.07	-0.29**		
Psychological Symptoms	-0.87**	-1.24	-0.50	0.19	-0.25**		
Model 2						0.22**	0.21**
Constant	-4.07**	-5.73	-2.41	0.84			
Hours of Sleep (per night)	0.79**	0.23	1.36	0.29	0.14**		
Physical Symptoms	-0.37**	-0.51	-0.23	0.07	-0.28**		
Psychological Symptoms	-0.91**	-1.28	-0.54	0.19	-0.26**		

*Note.* Model = “Enter” methods in SPSS statistics; *B*= unstandardised regression coefficient; *CI*= confidence interval; *LL*= lower limit; *UL*= upper limit; *SE B*= standard error of the coefficient;  $\beta$ = standardised coefficient;  $R^2$ = *coefficient of determination*;  $\Delta R^2$ = adjusted  $R^2$ .

$n=305$

\* $p=0.02$

\*\*  $p < 0.01$

## Discussion

### 4.1 Overview

This study used a mixed methods approach to explore the gaps in the literature regarding our understanding of the impact of surgically diagnosed endometriosis on family and friend relationships and engagement at social events. Specifically, this study looked to quantify this impact, examine its effect on participants QoL, and attempt to identify variables that may contribute to a participant’s ISS.

Using the data pool collected by a previous study, the current study follows from the findings that highlight the relationship between surgically diagnosed endometriosis and women's social participation (Mastrangelo, 2019). Content analysis was used to address the first aim of this study; determine what kind of impact surgically diagnosed endometriosis may have on participants' relationships with their family and friends and engagement at social events. This analysis reveals there are a range of experiences concerning the impact of endometriosis. Only 9.7% of participants received a positive score and only 2.7% scored neutrally on the newly created ISS. The majority of participants, 87.6%, scored negatively. This is in line with the literature that focuses on the effects that endometriosis can have on women's relationships with their family and friends and engagement at social events (Culley et al., 2013; Mastrangelo, 2019; Mellado et al., 2015; Gilmour et al., 2008; Moradi et al., 2014).

The existing literature emphasises the variety of ways women are affected by endometriosis, its physical and psychological impacts, and its effects both in their personal and professional lives (Mastrangelo, 2019; Gao et al., 2006). In order to address such a wide range of issues, which are not often examined in conjunction, the second aim of this study was to explore the relationships between the impact of endometriosis on family and friend relationships and engagement at social events, as measured by the ISS, and various QoL measures (Culley et al., 2013; Moradi et al., 2014; Mastrangelo, 2019).

Hypothesis one was supported: there was a statistically significant, weak correlation between the ISS and each domain of the WHOQoL-BREF. This finding is in line with studies that have found women dealing with the impact of endometriosis report a negative effect on a



range of QoL issues (Rush et al., 2019; Roomaney & Kagee, 2016). Hypothesis two was not supported: The Social Relationship Domain did not have a stronger correlation with the ISS than the other domains of the WHOQoL-BREF; Psychological; Physical; and Environment. Whilst this is not what was expected, it is in line with research that highlights the probable two-way relationship between some of these domains. Many researchers highlight the interplay between chronic pain and psychological distress, both commonly experienced by sufferers of endometriosis, and the extent to which this complex relationship may have an effect on the patient's ability to actively participate in many areas of life (Evans & Bush, 2006; Jones et al., 2004b).

Hypothesis three was supported: a statistically significant, weak, negative correlation was identified between all areas of the DASS-42 and the ISS. Hypothesis four was also supported: a stronger relationship was found between depression and the ISS than was found between anxiety or stress and the ISS. As highlighted by Santini et al, 2015, depression can have a large impact on relationships and vice versa with perceived support playing a protective role in the association between a chronic illness and depression (Santini et al., 2015). As Other's Comprehension of endometriosis was a content area identified in the small sample content analysis and was emphasised by Mastrangelo and Van Niekerk et al., this may contribute to the slightly stronger correlation between depression and the ISS over the other areas of the DASS-42 (Mastrangelo, 2019; Van Niekerk et al., 2020).

As Health Related QoL (HRQoL) measures have become more popular in the past decade to measure a patient's progress, disease-specific measures have also emerged as a valid way to assess specific health related concerns that are unique to a particular condition (Rizwana & Ashraf, 2018). Being led by previous literature the EHP-5 was included as an

endometriosis-specific HRQoL alongside the generic WHOQoL-BREF. This was so that no vital endometriosis-specific elements, such as fear of infertility or frustration at unsuccessful treatment, would be excluded from investigation. Hypothesis 5, addressing the relationship between both parts of the EHP-5 and the ISS, was supported: results showed a statistically significant, negative relationship. These findings are in line with the research conducted by the creator of the EHP-5 (Jones et al., 2001).

The third and final aim of this study was to examine what influence participants' general and endometriosis-specific variables had on their ISS. This influence was measured using a standard multiple regression analysis. The variables initially considered for the modelling were: Years between Onset & Diagnosis; Psychological Symptoms; Physical Symptoms; Hours of sleep (per night); Social events; and Time with Family and Friends. Contrary to expectations the variable Years between Onset & Diagnosis was not found to have a statistically significant correlation with ISS and had to be removed from the model. As this concept of delayed diagnosis was oft cited as having significant negative impact on women's physical and psychological health in previous literature, it was surprising to find no significant correlation (Apers et al., 2017; Jones et al., 2004a; Moradi et al., 2014). This may be explained when examining the questions these previous studies asked, as they asked participants to recall their feelings pre-diagnosis. When looking at studies that examine women's feelings post-diagnosis, women report an overwhelming sense of relief at having an explanation and validation for their pain (Ballard et al., 2006). Additionally, some papers examining chronic illnesses, aside from endometriosis, highlight the resilience patients can develop (Ferguson & Walker, 2012; Garrido-Hernansaiz et al., 2020). Perhaps the delay in diagnosis forced women to create their own coping strategies with their family and friends. This theory may explain the surprising lack of correlation.

The standard multiple regression modelling ultimately included five variables: Psychological Symptoms; Physical Symptoms; Hours of sleep (per night); time spent at Social events; and Time with Family and Friends. As Hours of sleep (per night), time spent at Social events, and Time with Family and Friends were all positive within the model, indicating they contribute to endometriosis having a positive impact on women's family and friend relationships and engagement at social events, this suggests that these variables are protective. Research conducted by Ailshire and Burgand (2012) shows that supportive family relationships are associated with better sleep while terse family relationships are associated with more disturbed sleep, and this is in line with the findings suggesting that participants who reported getting a higher quantity of sleep were more likely to have a higher ISS score (Ailshire & Burgand, 2012). The same can be said of time spent at Social Events and Time with Family and Friends. As outlined previously, social relationships play a critical role in overall human health, so this discovery is in line with previous literature (Seeman, 1996; Kutschke et al., 2018). Both of these two variables, Time Spent at Social Events and Time with Family and Friends, were non-significant within the standard multiple regression model. Therefore, we are unable to have confidence in this modelling and accept this explanation of variance as valid.

The two negative variables identified within the modelling were Psychological Symptoms and Physical Symptoms. This suggests that participants with more symptoms are more likely to have a lower ISS and, subsequently, their endometriosis is more likely to have a negative impact on family and friend relationships and engagement at social events. Previous literature supports this finding (Evans & Bush, 2006; Culley et al., 2013; Wilson et al., 2020). It is important to note that the standard multiple regression modelling violated test

assumptions so we cannot have confidence when interpreting these results, and this limits the value of our findings (Laerd Statistics, 2015).

#### ***4.2 Strengths of Current Study***

Minimal mixed methods research has been conducted within this area of study with the qualitative research being limited to smaller sample sizes and the larger quantitative studies often being sourced from pain clinics, thus restricting findings from being representative and generalisable to a wider population (Denny, 2004; Culley et al., 2013; Hållstam et al., 2018; Evans et al., 2019; Gambadauro et al., 2019). The current study was able to examine a larger sample size, 331 participants, sourced from a variety of places including social media, medical clinics, and radio listeners. This has potentially increased the generalisability of the study to the wider endometriosis community. As the survey was conducted entirely online, this minimised the participant burden regarding response time (Mastrangelo, 2019).

Content analysis was relied upon in this study and there is always a degree of subjectivity involved when using this method. In order to combat this subjectivity, and ensure validity and reliability of the analysis, the coding rules (Appendix E) and a sample of the completed coding were cross-checked by a second researcher (Mayring, 2000; Elo & Kyngäs, 2008).

Additionally, the current study included the leading endometriosis specific HRQoL measure in order to ensure the relevant endometriosis specific information was collected from participants alongside the generic measures (Rizwana & Ashraf, 2018).

### ***4.3 Limitations and Methodological Considerations***

Key limitations and methodological considerations should be taken into account when interpreting the results of the current study. A number of variables included in the standard multiple regression modelling relied on self-reported measures collected from the online survey. Whilst participants may have been able to correctly report how many hours a week they spent at parties or with family, their ability to correctly estimate how many hours of sleep they got per night may have been less reliable.

This is also true of the participants' self-reported symptoms, where use of different language to describe an issue could lead to a dramatically different symptom count, i.e. stomach symptoms could be listed simply as IBS (one symptom) or separately as stomach pain, constipation, food sensitivities (three symptoms). Also, these were participants' subjective views of their symptoms and were not verified by a medical professional. As such, an alternative future researcher may wish to consider clustering symptom types or give participants a list of symptoms from which to choose.

Additionally, the data violated several important test assumptions for the standard multiple regression modelling. Despite the larger data set protecting against smaller violations, the violation of linearity and homoscedasticity severely limits the validity of these results. One possible reason this occurred may have been the way some of the data were collected. All Estimated Lifestyle Question response data were collected in discrete ranges, as outlined in the methods section, changing it from a continuous numerical variable into ordinal numerical categories (Laerd Statistics, 2015). Adjusting this data collection strategy may result in more robust modelling.

#### ***4.4 Implications and Recommendations for Future Research***

This study aims to contribute to the growing field of endometriosis literature focusing on the impact that surgically diagnosed symptomatic endometriosis has on women's relationships with family and friends and engagement at social events. Furthermore, this study hopes to provide insight into what variables may pose a risk or be protective of women's relationships. We also hope to show that there can be positive outcomes and increased intimacy in the lives of endometriosis sufferers despite the challenges they face.

Investigation is needed into the possible mediating variable of Others' Comprehension: a sufferer's family and friend's understanding of endometriosis. This concept reoccurred frequently within participants' responses and previous literature (Mellado et al., 2015; Mastrangelo, 2019; Wilson et al., 2020). When assessing the time spent with family or friends, understanding and support could dramatically change the value of the interaction. As the public becomes more aware of endometriosis, this should be given more attention.

The past literature suggests that the traumatic experience of a significant delay in diagnosis can have a substantial effect on patient outcomes (Apers et al., 2017; Jones et al., 2004b; Moradi et al., 2014). The surprising lack of correlation found in this research suggests that more research into this delay would be beneficial. Investigating the consequences immediately after diagnosis and the effect of receiving a long-awaited answer may prove beneficial to improving support for the patient, including garnering understanding from family and friends.

In addition to investigating the two concepts listed above, future research should also examine age-related endometriosis differences and analyse how the experiences of adolescents, young adults, and middle-aged women are distinct from each other (Gilmour et al., 2008; Culley et al., 2013). Not only would this allow for investigation into the post-diagnosis impact of changes to family and friend's understanding of endometriosis but would allow examination of the different stages of women's social lives.

Social relationships have a large influence on human health and QoL, so understanding the impact of endometriosis on these relationships has important implications for the clinical management of endometriosis and should be taken into account when formulating a patient's individual treatment plan.

#### ***4.5 Conclusion***

Content analysis shows the overwhelming impact of surgically diagnosed, symptomatic endometriosis on women's relationships with their family and friends and engagement at social events is negative, with a small portion of participants reporting a neutral or positive impact. Quantitative analysis indicates there is a relationship between the impact of endometriosis and lower levels of health status, reduced quality of life, and higher levels of psychological distress. A multiple regression analysis indicates that: hours slept per night; the amount of physical and psychological symptoms; time spent with family and friends; and time at social events exert some influence over the impact of endometriosis on women's relationship with their family and friends, however the data violated key test assumptions so these results are not valid. Further research is needed in this area to understand the complex and nuanced issues women with endometriosis face as they navigate their family and friend relationships and engagement at social events.

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## Appendices

### Appendix A - Online Survey

#### **Social Participation in Women with Symptomatic Endometriosis Screening Questions**

**\* 1. Are you over the age of 18?**

Yes

No

**\* 2. Do you have a surgical diagnosis of endometriosis?**

Yes

No

**\* 3. Does your endometriosis cause symptoms of any kind?**

Yes

No

**\* 4. Do you currently reside within Australia?**

Yes

No

**Social Participation in Women with Symptomatic Endometriosis**  
**World Health Organisation Quality of Life (WHOQoL-BREF)**

**\* 5. This assessment asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.**

**Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks.**

Please read each question, assess your feelings, and select the number on the scale for each question that gives the best answer for you.

	Very poor	Poor	Neither poor nor good	Good	Very good
(G1) How would you rate your quality of life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**\* 6. Please read each question, assess your feelings, and select the number on the scale for each question that gives the best answer for you.**

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
(G4) How satisfied are you with your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**\* 7. The following questions ask about how much you have experienced certain things in the last two weeks.**

	Not at all	A little	A moderate amount	Very much	An extreme amount
(F1.4) To what extent do you feel that physical pain prevents you from doing what you need to do?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F11.3) How much do you need any medical treatment to function in your daily life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F24.2) How much do you enjoy life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F24.2) To what extent do you feel your life to be meaningful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**\* 8. The following questions ask about how much you have experienced certain things in the last two weeks.**

	Not at all	A little	A moderate amount	Very much	Extremely
(F5.3) How well are you able to concentrate?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F16.1) How safe do you feel in your daily life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F22.1) How healthy is your physical environment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**\* 9. The following questions ask about how completely you experience or were able to do certain things in the last two weeks.**

	Not at all	A little	Moderately	Mostly	Completely
(F2.1) Do you have enough energy for everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F7.1) Are you able to accept your bodily appearance?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F18.1) Have you enough money to meet your needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F20.1) How available to you is the information that you need in your day-to-day life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F21.1) To what extent do you have the opportunity for leisure activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**\* 10. The following question asks about how completely you experience or were able to do certain things in the last two weeks.**

	Very poor	Poor	Neither	Good	Very good
(F9.1) How well are you able to get around?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**\* 11. The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.**

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
(F3.3) How satisfied are you with your sleep?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
(F10.3) How satisfied are you with your ability to perform your daily living activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F12.4) How satisfied are you with your capacity for work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F6.3) How satisfied are you with yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F13.3) How satisfied are you with your personal relationships?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F15.3) How satisfied are you with your sex life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F14.4) How satisfied are you with the support you get from your friends?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F17.3) How satisfied are you with the conditions of your living place?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F19.3) How satisfied are you with your access to health services?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F23.3) How satisfied are you with your transport?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



**\* 12. The following question refers to how often you have felt or experienced certain things in the last two weeks.**

	Never	Seldom	Quite often	Very often	Always
(F8.1) How often do you have negative feelings such as blue mood, despair, anxiety, depression?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Social Participation in Women with Symptomatic Endometriosis**

**Short-Form Endometriosis Health Profile (EHP-5)**

**\* 13. Part 1: During the last 4 weeks, how often because of your endometriosis have you...**

	Never	Rarely	Sometimes	Often	Always
<b>1 Found it difficult to walk because of the pain</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>2 Felt as though symptoms are ruling your life?</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>3 Had mood swings?</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>4 Felt others do not understand what you are going through?</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>5 Felt your appearance has been affected?</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



**Social Participation in Women with Symptomatic Endometriosis**  
**Depression Anxiety Stress Scale (DASS)**

**\* 15. Please read each statement and select a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.**

*The rating scale is as follows:*

0 Did not apply to me at all  
 1 Applied to me to some degree, or some of the time  
 2 Applied to me to a considerable degree, or a good part of time 3 Applied to me very much, or most of the time

	0	1	2	3
1 I found myself getting upset by quite trivial things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2 I was aware of dryness of my mouth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3 I couldn't seem to experience any positive feeling at all	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4 I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5 I just couldn't seem to get going	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6 I tended to over-react to situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	0	1	2	3
7 I had a feeling of shakiness (eg, legs going to give way)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8 I found it difficult to relax	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9 I found myself in situations that made me so anxious I was most relieved when they ended	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10 I felt that I had nothing to look forward to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11 I found myself getting upset rather easily	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12 I felt that I was using a lot of nervous energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13 I felt sad and depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14 I found myself getting impatient when I was delayed in any way (eg, elevators, traffic lights, being kept waiting)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15 I had a feeling of faintness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16 I felt that I had lost interest in just about everything	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17 I felt I wasn't worth much as a person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	0	1	2	3
18 I felt that I was rather touchy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19 I perspired noticeably (eg, hands sweaty) in the absence of high temperatures or physical exertion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20 I felt scared without any good reason	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21 I felt that life wasn't worthwhile	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22 I found it hard to wind down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23 I had difficulty in swallowing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24 I couldn't seem to get any enjoyment out of the things I did	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25 I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26 I felt down-hearted and blue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27 I found that I was very irritable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	0	1	2	3
28 I felt I was close to panic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29 I found it hard to calm down after something upset me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30 I feared that I would be "thrown" by some trivial but unfamiliar task	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31 I was unable to become enthusiastic about anything	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32 I found it difficult to tolerate interruptions to what I was doing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33 I was in a state of nervous tension	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34 I felt I was pretty worthless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35 I was intolerant of anything that kept me from getting on with what I was doing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
36 I felt terrified	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
37 I could see nothing in the future to be hopeful about	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
38 I felt that life was meaningless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	0	1	2	3
39 I found myself getting agitated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
40 I was worried about situations in which I might panic and make a fool of myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
41 I experienced trembling (eg, in the hands)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
42 I found it difficult to work up the initiative to do things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



## **Social Participation in Women with Symptomatic Endometriosis**

### **Open-Ended Questions**

- Please discuss the following open-ended questions with as much detail as possible.
- Please be as open as possible and feel free to write as much as you wish.
- Remember any information provided will not be identified within the final thesis.

**\* 16. How has endometriosis had an overall impact on your life?**

**\* 17. How has your experience with endometriosis impacted on your social interaction with your family (immediate and extended)?**

**\* 18. How has your experience with endometriosis impacted on your social interaction with friendships and relationships with friends?**

**19. How has your experience with endometriosis impacted on your work or education?**

- Is your employer/ institution aware of your endometriosis diagnosis?
- Are they understanding and/or supportive?

\* 20. How has your experience with endometriosis impacted upon your attendance and engagement at social events (e.g. gatherings, parties, lunches, etc.)?

\* 21. How has your experience with endometriosis impacted on your engagement in leisure activities (e.g. netball, hiking, swimming, etc.)?

\* 22. How has your experience with endometriosis impacted your engagement in household tasks (e.g. cleaning, gardening, grocery shopping, etc.)?

## Social Participation in Women with Symptomatic Endometriosis

### Questions about you

\* 23. What is your age (in years)?

\* 24. What is your present marital status?

Married

Widowed

Single

Divorced

In a relationship

Separated but not divorced

Other (please specify)

\* 25. What is your sexuality?

Heterosexual

Homosexual

Bisexual

Prefer not to say

Other (please specify)

\* 26. Who do you currently reside with in your household?

**\* 27. Are you of Aboriginal or Torres Strait Islander origin?**

- No
- Yes, Aboriginal
- Yes, Torres Strait Islander

**\* 28. In which country were you born?**

- Australia
- England
- New Zealand
- India
- Other (please specify)
- Italy
- Vietnam
- Philippines

**\* 29. Are you currently attending a school or any other education institution?**

- No
- Yes, full-time student
- Yes, part-time student

**\* 30. What type of education institution are you attending?**

- University or other higher education institution
- Technical or further education institution (including TAFE Colleges)
- N/A
- Other education institution (please specify)

\* 31. What is the highest year of primary or secondary school you have completed?

- Year 12 or equivalent
- Year 11 or equivalent
- Year 10 or equivalent
- Year 9 or equivalent
- Year 8 or below
- Did not attend school

\* 32. What is the level of the highest qualification you have completed?

For example: TRADE CERTIFICATE, BACHELOR DEGREE, ASSOCIATE DIPLOMA CERTIFICATE II, ADVANCED DIPLOMA.

- N/A
- Please specify

\* 33. What is the main field of study for your highest qualification completed?

For example: PLUMBING, HISTORY, PRIMARY SCHOOL TEACHING, HAIRDRESSING, GREENKEEPING.

- N/A
- Please specify

\* 34. How many children do you have?

- None
- 1
- 2
- 3
- 4
- 5+

**\* 35. Do you have a job of any kind?**

- Yes, casually employed
- Yes, employed part-time
- Yes, employed full-time
- Yes, but currently on leave (please specify - e.g. annual leave, long-service leave, maternity leave, carers leave, etc.)
- Yes, unpaid work in a family business
- Yes, other unpaid work
- No, do not have a job

**\* 36. Approximately how many hours of paid work do you do per week?**

- N/A
- 5 hours or less
- 5-10 hours
- 11-15 hours
- 16-25 hours
- 26-35 hours
- 36 or more hours

**\* 37. Approximately how many hours do you sleep each night?**

- 4 hours or less
- 5-6 hours
- 7-8 hours
- 9+ hours

**\* 38. Approximately how many hours do you spend with your friends and/or family per week (e.g. gatherings, parties, lunches)**

- 0 hours
- 1 hour or less
- 1-3 hours
- 4-6 hours
- 7-9 hours
- 10+ hours

\* 39. Approximately how many hours do you spend at social events per week (e.g. gatherings, parties, lunches, etc.)

- |                                      |                                 |
|--------------------------------------|---------------------------------|
| <input type="radio"/> 0 hours        | <input type="radio"/> 4-6 hours |
| <input type="radio"/> 1 hour or less | <input type="radio"/> 7-9 hours |
| <input type="radio"/> 1-3 hours      | <input type="radio"/> 10+ hours |

\* 40. Approximately how many hours do you engage in leisurely activities per week? (e.g. netball, hiking, swimming, etc.)

- |                                      |                                 |
|--------------------------------------|---------------------------------|
| <input type="radio"/> 0 hours        | <input type="radio"/> 4-6 hours |
| <input type="radio"/> 1 hour or less | <input type="radio"/> 7-9 hours |
| <input type="radio"/> 1-3 hours      | <input type="radio"/> 10+ hours |

\* 41. Approximately how many hours do you spend doing general household tasks per week? (e.g. cleaning, gardening, cooking, grocery shopping, etc.)

- |                                      |                                 |
|--------------------------------------|---------------------------------|
| <input type="radio"/> 0 hours        | <input type="radio"/> 4-6 hours |
| <input type="radio"/> 1 hour or less | <input type="radio"/> 7-9 hours |
| <input type="radio"/> 1-3 hours      | <input type="radio"/> 10+ hours |

## Social Participation in Women with Symptomatic Endometriosis

### Questions about your experience with endometriosis

\* 42. What symptoms do you have as a result of your endometriosis? (physical or psychological)

\* 43. What treatments or surgeries have you undergone for treatment of your endometriosis (you may select more than one option)?

- Ablation laparoscopic surgery
- Extraction laparoscopic surgery
- Hysterectomy
- Hormonal contraceptives
- Other (please specify)

\* 44. How many laparoscopic surgeries have you undergone for your endometriosis since diagnosis?

- None
- 1
- 2
- 3
- 4
- 5+



\* 45. At what age did your onset of endometriosis symptoms occur?

- |                                |                             |
|--------------------------------|-----------------------------|
| <input type="radio"/> Under 18 | <input type="radio"/> 45-54 |
| <input type="radio"/> 18-24    | <input type="radio"/> 55-64 |
| <input type="radio"/> 25-34    | <input type="radio"/> 65+   |
| <input type="radio"/> 35-44    |                             |

\* 46. At what age did you receive a surgical diagnosis of endometriosis?

- |                                |                             |
|--------------------------------|-----------------------------|
| <input type="radio"/> Under 18 | <input type="radio"/> 45-54 |
| <input type="radio"/> 18-24    | <input type="radio"/> 55-64 |
| <input type="radio"/> 25-34    | <input type="radio"/> 65+   |
| <input type="radio"/> 35-44    |                             |

\* 47. From the onset of endometriosis symptoms, how long did it take to receive a surgical diagnosis of endometriosis?

- |                                |                                 |
|--------------------------------|---------------------------------|
| <input type="radio"/> 0-1 year | <input type="radio"/> 6 years   |
| <input type="radio"/> 2 years  | <input type="radio"/> 7 years   |
| <input type="radio"/> 3 years  | <input type="radio"/> 8 years   |
| <input type="radio"/> 4 years  | <input type="radio"/> 9 years   |
| <input type="radio"/> 5 years  | <input type="radio"/> 10+ years |

## **Social Participation in Women with Symptomatic Endometriosis**

### **Endometriosis Australia Support Groups**

If you have experienced any feelings of distress due to participation in this survey, please do not hesitate to contact your GP for a referral to a Mental Health Service provider or contact [Lifeline Australia](#), a national charity providing all Australians experiencing a personal crisis with access to 24 hour crisis support and suicide prevention services.

The following link will direct you to the [Endometriosis Australia Support Groups](#) to locate your nearest support group.

If you would like your test results to be forwarded to your GP, please leave GP and your personal contact details below (NOTE: Please complete contact details in entirety).

If you are interested in the outcome of this research, feel free to leave your email address to be forwarded a summary of key research findings at completion of the project.

#### **48. OPTIONAL: GP contact details**

Name

Address

City/Town

State/Province

ZIP/Postal Code

#### **49. OPTIONAL: Participant contact details**

Name

Address

City/Town

State/Province

ZIP/Postal Code

**50. OPTIONAL: Participant email address**

Email Address

## Appendix B – Participant Information Sheet

**PARTICIPANT INFORMATION SHEET**

**PROJECT TITLE: The impact of symptomatic endometriosis on women's social participation**

**HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2018-097**

**PRINCIPAL INVESTIGATOR: Professor Deborah Turnbull**

**STUDENT RESEARCHER: Melody Georgia Mastrangelo**

**STUDENT'S DEGREE: Bachelor of Psychological Science - Honours**

Dear Participant,

You are invited to participate in the research project described below.

**What is the project about?**

This project will examine endometriosis; a chronic condition that affects 1 in 10 women of reproductive age. Endometriosis can only be discovered through laparoscopic surgery which for many women, results in a significant delay in diagnosis. Symptoms of endometriosis can include chronic pain, infertility and mental health issues such as depression and anxiety. A considerable amount of research into women's experiences with endometriosis has focused on physical and mental health. The social impact of endometriosis however, has been very much overlooked and therefore left unexplored. The aim of this study is to gain an insight and understanding of the social experience for women with symptomatic endometriosis with regards to family and friend relationships, work and education, attendance at social events, leisure activities and general household tasks.

**Who is undertaking the project?**

This project is being conducted by Melody Mastrangelo. This research will form the basis for the degree of Bachelor of Psychological Science (Honours) at The University of Adelaide under the supervision of Professor Deborah Turnbull.

**Why am I being invited to participate?**

You are eligible to participate in this project if you:

- Are over 18 years of age
- Have a surgical diagnosis of endometriosis
- Have symptoms associated with your endometriosis
- Currently reside within Australia

**What am I being invited to do?**

You are being invited to complete an online survey consisting of 115 questions (multiple choice, short answer and open-ended). The survey comprises of seven sections;

1. Screening questions regarding your eligibility to participate
2. The World Health Organisation Quality of Life (WHOQoL-BREF) used to assess quality of life
3. Short-Form Endometriosis Health Profile (EHP-5) used to measure the wide range of effects that endometriosis can have on women's lives
4. Depression Anxiety Stress Scale (DASS) used to measure the three related emotional states of depression, anxiety and tension/stress
5. 6 open-ended questions asking about your overall experience of endometriosis with specific regard to the effect on your family and friend relationships, work and education, attendance at social events, leisure activities and general household tasks

6. Questions about you
7. Questions about your experience with endometriosis

**How much time will my involvement in the project take?**

It is estimated that involvement in the online survey will take approximately 25 minutes. The online survey can be completed in your own time at your own convenience.

**Are there any risks associated with participating in this project?**

Foreseeable risks for participation in this online survey are minimal. The researcher has taken into consideration the fact that living with endometriosis itself can be very distressing. Possible areas of burden include inconvenience and emotional distress. Inconvenience may be experienced by time taken to complete the online survey (approximately 25 minutes). Psychological harm may be experienced by potential feelings of distress surrounding disclosure of sensitive information about your experience with endometriosis.

If you do experience any feelings of distress, please do not hesitate to contact your GP for a referral to a Mental Health Service provider. You can also contact Lifeline Australia on 13 11 14 for 24-hour crisis support and suicide prevention or visit the following Endometriosis Australia Support Group page to find the nearest support group to you (<https://www.endometriosisaustralia.org/support-groups>).

**What are the potential benefits of the research project?**

The potential benefit of this study (which is by no means assured) is the potential contribution to this area of endometriosis research. Another potential benefit is information regarding access to the Endometriosis Australia Support Groups website for access to endometriosis specific support services within your State/Territory. Additionally, the option to have test results forwarded to your GP. Finally, a summary of key research findings can be sent to you at completion of the project.

**Can I withdraw from the project?**

Participation in this project is completely voluntary. If you choose to participate, you can withdraw from the study at any point up until submission of the online survey.

**What will happen to my information?**

*Confidentiality and privacy:* Participation in this study is completely confidential and anonymous unless agreeable by you. Identifiable information will not be gathered at any point of this study unless agreed to by you. The researcher will take utmost care to ensure that direct quotes sourced from the survey will only be used if entirely non-identifiable. At conclusion of the survey, you will have the option to leave your name and address and the name and address of your GP to have their test results forwarded your GP. You will also be given the option to leave your email address should you be interested in the outcome of the research in order to be forwarded a summary of key research findings at completion of the project.

*Storage:* Data gathered from the online survey will be stored within the SurveyMonkey portal. All associated data will be stored on the Student (S) Drive, a secure password protected site only accessible by the research student and Supervisor. Data will be stored for a minimum of five years.

*Publishing:* The main use of this research is to form the basis for the degree of Bachelor of Psychological Science (Honours) thesis. All information and results from this project will be reported within the thesis. Should this project be of a publishable standard, it will be made publicly accessible in the form of a publication or journal article. As discussed, participation in this study maintains complete confidentiality and anonymity.

Your information will only be used as described in this participant information sheet and it will only be disclosed according to the consent provided, except as required by law.

**Who do I contact if I have questions, concerns or a complaint about the project?**

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2018-097). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research 2007 (Updated 2018).

[Redacted contact information]

If you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone: +61 8 8313 6028  
Email: [hrec@adelaide.edu.au](mailto:hrec@adelaide.edu.au)  
Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

**If I want to participate, what do I do?**

If you have read the participation information sheet and wish to participate within this study, please click 'NEXT' to begin the online survey. Completion and submission of the online survey implies full consent.


Yours sincerely,

**Melody Mastrangelo**  
Student Researcher

**Professor Deborah Turnbull**  
Principal Investigator



Appendix D – Poster Modified for Social Media



HREC Approval Number: H-2019-097

THE UNIVERSITY  
of ADELAIDE

## Do you have surgically diagnosed symptomatic endometriosis?

Are you over the age of 18 and currently residing in Australia?

**Project title: The Impact of Symptomatic Endometriosis on Women's Social Participation**

Endometriosis currently affects **1 in 10** Australian women of reproductive age

Most common **symptoms** of endometriosis include chronic pelvic pain (CPP), painful periods, painful intercourse, infertility and mental health problems such as depression and anxiety

For many women, these symptoms can take a toll on their **social lives** whether it be relationships with friends and family, attendance at social events, impact on work and/or education and engagement in leisurely activities

Taking part in the **25 minute** survey is entirely **confidential** and **anonymous** unless agreeable by you. The survey consists of **multiple choice** and **short-answer questions** that will tell us a little about you and your experience with endometriosis

This thesis will form the basis for the degree of Bachelor of Psychological Science (Honours)

**For further information or to participate head to the link** [redacted]



## Appendix E - Content Analysis Coding Guidelines

**Coding Guidelines**

- Each statement 'fragment' will be counted.
- A fragment is a word or small collection of words that sufficiently adds to or differs from the sentiment.
- Fragments will still be treated separately even if they are related.
- Contextual fragments will not be counted.
- Pain or symptom statements given to explain or qualify an impact will be considered contextual and not counted.
- Statements of non-disclosure will be coded as neutral
- "Try" statements (i.e. 'I go as often as I can.' 'I try to attend as many things as possible.' 'I'd still make an effort.') will be coded as neutral
- Family/Friend statements of caring (i.e. 'it impacts them because they worry and stress about me.' 'frustrated that they cannot do anything to help.') will be coded as neutral.
- Ambiguous statements (i.e. 'Stopped going to gym before my laparoscopy.') should not be counted.

## Appendix F - Mastrangelo's HREC Approval



**RESEARCH SERVICES**  
OFFICE OF RESEARCH ETHICS, COMPLIANCE  
AND INTEGRITY  
THE UNIVERSITY OF ADELAIDE

LEVEL 4, RUNDLE MALL PLAZA  
50 RUNDLE MALL  
ADELAIDE SA 5000 AUSTRALIA

TELEPHONE +61 8 8313 5137  
FACSIMILE +61 8 8313 3700  
EMAIL hrec@adelaide.edu.au

CRICOS Provider Number 00123M

Our reference 33669

12 June 2019

Professor Deborah Turnbull  
Psychology

Dear Professor Turnbull

**ETHICS APPROVAL No:** H-2019-097  
**PROJECT TITLE:** The impact of symptomatic endometriosis on women's social participation

The ethics application for the above project has been reviewed by the Human Research Ethics Committee and is deemed to meet the requirements of the *National Statement on Ethical Conduct in Human Research 2007 (Updated 2018)*.

You are authorised to commence your research on: 12/06/2019  
The ethics expiry date for this project is: 30/06/2022

**NAMED INVESTIGATORS:**

Chief Investigator: Professor Deborah Turnbull  
Student - Undergraduate Bachelors Honours: Miss Melody Georgia Mastrangelo

**CONDITIONS OF APPROVAL:** Thank you for your considered responses to the matters raised. The revised application provided on 05/06/19 and amended documentation provided on 12/06/19 has been approved.

Ethics approval is granted for three years and is subject to satisfactory annual reporting. The form titled Annual Report on Project Status is to be used when reporting annual progress and project completion and can be downloaded at <http://www.adelaide.edu.au/research-services/oreci/human/reporting/>. Prior to expiry, ethics approval may be extended for a further period.

Participants in the study are to be given a copy of the information sheet and the signed consent form to retain. It is also a condition of approval that you immediately report anything which might warrant review of ethical approval including:

- serious or unexpected adverse effects on participants,
- previously unforeseen events which might affect continued ethical acceptability of the project,
- proposed changes to the protocol or project investigators; and
- the project is discontinued before the expected date of completion.

Yours sincerely,

Dr Tiffany Gill  
Acting Chair

The University of Adelaide

## Appendix G - Current Study HREC Approval



**RESEARCH SERVICES**  
OFFICE OF RESEARCH ETHICS, COMPLIANCE  
AND INTEGRITY  
THE UNIVERSITY OF ADELAIDE

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50 RUNDLE MALL  
ADELAIDE SA 5000 AUSTRALIA

TELEPHONE +61 8 8313 5137  
FACSIMILE +61 8 8313 3700  
EMAIL hrec@adelaide.edu.au

CRICOS Provider Number 00123M

Our reference 34513

29 June 2020

Professor Deborah Turnbull  
Psychology

Dear Professor Turnbull

**ETHICS APPROVAL No:** H-2020-111  
**PROJECT TITLE:** Examining the Impact of Surgically Diagnosed Endometriosis on  
Family and Friend Relationships

The ethics application for the above project has been reviewed by the Human Research Ethics Committee and is deemed to meet the requirements of the *National Statement on Ethical Conduct in Human Research 2007 (Updated 2018)*.

You are authorised to commence your research on: 29/06/2020  
The ethics expiry date for this project is: 30/06/2023

**NAMED INVESTIGATORS:**

Chief Investigator:	Professor Deborah Turnbull
Student - Undergraduate Bachelors Honours:	Ms Tessa Price-Brooks
Associate Investigator:	Miss Melody Georgia Mastrangelo

**CONDITIONS OF APPROVAL:** Thank you for addressing the feedback. The application received on the 18th of May 2020 has been approved.

Ethics approval is granted for three years and is subject to satisfactory annual reporting. The form titled Annual Report on Project Status is to be used when reporting annual progress and project completion and can be downloaded at <http://www.adelaide.edu.au/research-services/oreci/human/reporting/>. Prior to expiry, ethics approval may be extended for a further period.

Participants in the study are to be given a copy of the information sheet and the signed consent form to retain. It is also a condition of approval that you immediately report anything which might warrant review of ethical approval including:

- serious or unexpected adverse effects on participants,
- previously unforeseen events which might affect continued ethical acceptability of the project,
- proposed changes to the protocol or project investigators; and
- the project is discontinued before the expected date of completion.