

The \$6 Billion Woman and the \$600 Million Girl



endorsed by:



the PELVIC PAIN report

This report is an Australian initiative to address human and fiscal burdens associated with conditions causing pelvic pain. It provides solutions to improve women's health services and outcomes. The intended audiences for the Pelvic Pain Report are state and federal governments, funders, clinicians, consumers, allied health care professionals, researchers and research funders.

Pelvic Pain Steering Committee:

Deborah Bush QSM

*- CEO and Founder Endometriosis New Zealand,
Advocate for women's health, and development of
innovative health service provision.*

Dr Susan Evans

*- Gynaecologist, Pain Medicine Physician,
Specialist in pelvic pain.*

Professor Thierry Vancaillie

*- Gynaecologist, Pain Medicine Physician,
Specialist in pelvic pain*

“Pelvic pain, while common, is often a hidden burden to the lives of many women. With emerging national and international knowledge about pain and the heavy toll it poses on individuals and society, it is timely that this report ‘The \$6 Billion Woman and the \$600 Million Girl’ raises pelvic pain to public attention as an important health issue. This call for action is overdue in a much neglected area of health and healthcare impacting the lives of so many women and girls in our community.”

Dr Christine Bennett
- *MBBS FRACP Master Paed*
Professor and Dean, School of Medicine, Sydney
The University of Notre Dame Australia

“The Pelvic Pain Report comes at a key time point in the evolution of pain management as a significant moral, societal, healthcare and financial issue. The specific shortcomings and solutions for pain are reflected in the overall picture of the National Pain Strategy. However, pelvic pain has suffered from particularly inappropriate stigmatisation and neglect, with resulting disastrous effects on women and young girls. Thus I am very pleased to see this report giving due emphasis to the special needs of pelvic pain.”

Professor Michael Cousins AM
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Chairman National Pain Summit (Canberra 2010)
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TABLE OF CONTENTS

TITLE PAGE

THE PELVIC PAIN REPORT

FOREWORD 6

Dr David Jones – Dean, Faculty of Pain Medicine (FPM)

EXECUTIVE SUMMARY 8

PART ONE 10

BACKGROUND AND PROCESS 10

WHAT'S IN A NAME? 12

EXISTING INFORMATION 13

DEFINING PAIN 14

VISION and GOALS 16

The Pelvic Pain Report

Australian Government Department of Health and Ageing

Royal Australian and New Zealand College of Obstetricians and Gynaecologists

Faculty of Pain Medicine

Painaustralia and the National Pain Strategy

PART TWO 19

THE CASE FOR CHANGE 19

DEPARTMENT OF HEALTH AND AGEING POLICIES 21

CURRENT PROJECT RESULTS FROM THE ADVISORY AND PATIENT GROUPS 29

EXISTING TREATMENT GUIDELINES FOR ENDOMETRIOSIS 34

INTERDISCIPLINARY SERVICES FOR PELVIC PAIN IN AUSTRALIA 35

PELVIC PAIN ORGANISATIONS IN AUSTRALIA 36

SUMMARY OF PART TWO 37

PART THREE 39

RECOMMENDATIONS 39

PART FOUR 44

CONCLUSION 44

LIST OF ABBREVIATIONS 47

ACKNOWLEDGEMENTS 49

REFERENCES 50

APPENDICES 53

APPENDIX I	ENDOMETRIOSIS NEW ZEALAND	53
APPENDIX II	PATIENT CASE STUDIES AND SOCIAL NETWORK COMMENTS (May – July 2011)	58
APPENDIX III	EXISTING INTERNATIONAL GUIDELINES	64
APPENDIX IV	FIGURE 1 – MONETARY LOSS FROM ENDOMETRIOSIS	66
	FIGURE 2 - GRAPH TO SHOW TREND OF PRESENTATION IN ADOLESCENTS UNDER 20	
APPENDIX V	PELVIC PAIN STEERING COMMITTEE BIOGRAPHIES, ADVISORY GROUP AND REPORT REVIEWERS	67
	DEBORAH BUSH QSM	
	DR SUSAN EVANS	
	PROFESSOR THIERRY VANCAILLIE	
	ADVISORY GROUP	
	REPORT REVIEWERS	
APPENDIX VI	GRANTS; CONFLICT OF INTEREST; DISCLAIMER; COPYRIGHT	73

Foreword

Dr David Jones

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Dean, Faculty of Pain Medicine, ANZCA

For many chronic conditions the days of the insular clinician are fading in favour of big-picture approaches using multi-dimensional models, collaborating multi-skilled teams, and holistic strategies. There is no more evident a field to illustrate this than PAIN. A simple four-lettered word, but with a mountain range of meanings and effects.

Persistent Pelvic Pain (PPP) is one large subset of the pain spectrum, with the multitude of biologic, psychological and social impact factors in common with the rest of persistent (or chronic) pain conditions. From a medical perspective, the field of gynaecology is catching up with current understanding of the biology of persistent pain, particularly in the area of endometriosis - one condition contributing significant numbers to the persistent pelvic pain suffering population.

From a patient perspective, reluctance to present to health care providers probably plays a significant part. Specific concerns preventing presentation include the implications for her 'private life', her fertility, reproduction, and beliefs that a certain amount of suffering is 'normal'. Despite accelerating knowledge of the neurobiology contributing to persistent pain, sufferers have found many explanations for persisting pain to be uninformed or even somewhat dismissive.

Biologic alterations contributing to lasting pain are principally within the nervous system - which includes the brain. A relatively new realisation is that endometriosis contributes specific nervous system consequences - including the promotion of new nerve growth into endometriosis lesions, chemical stimulation of inflammatory processes, and inadvertent nerve damage consequences from surgical procedures directed at excising lesions. This makes it a truly multi-dimensional process from the biologic perspective alone, not to mention psychosocial and economic impacts.

At present there are no substantive physical prevention methods for either endometriosis or persistent pain, although early appropriate interventions can lessen its impact. This is in contrast to the beliefs of former times, when the advice was often 'give it time', or 'time heals'. For many affected women time does not heal, but instead is accompanied by a downwards spiral of distress, uncertainty about the future, and increasing sensitisation as part of the neurobiology. The impact of prolonged pain is especially evident in the psychological and cognitive-emotional responses of knowing that she has a long term condition. This is something that can have a major impact on her social, family and partner relationships, without an easy fix solution. A vicious cycle with deteriorating health can develop from anxiety, negativity, low mood, loss of productivity and sleep loss - leading to lowered

immune function and lost efficiency of natural central pain inhibiting mechanisms, to mention but a few.

Breaking into, or preventing this negative spiral, depends very much on having early factual information - i.e. education, engendering HOPE, and motivating more self efficacy. Clinical professionals can do their work well, but if in a vacuum which lacks the facts and motivation then its value is degraded. There is therefore a large role for education – whether for young adolescents and adults, or the wider population.

It is naïve to suggest persistent pelvic pain and endometriosis is only about women and their wellbeing. It, like all persistent pain, has consequences beyond the individual sufferer - into families, workplaces and relationships. This is coupled with huge economic implications for all of these, plus government's expenditure on health and welfare.

The strategy as outlined in *The \$6 Billion Woman and the \$600 Million Girl - The Pelvic Pain Report* brought together by the Pelvic Pain Steering Committee of Ms Bush, Dr Evans and Professor Vancaillie incorporates their multidisciplinary experience from clinical, scientific, education, business and motivational backgrounds. A steering function leads to needed action. One of the first actions needed is **ADVOCACY** of this strategy at all levels – government, insurers, health professionals in many fields, educators - especially of young people, and to the population at large. This is conceptually a part within the *National Pain Strategy*. It is a step on a journey to lessen that suffering, and work to redirect the already enormous expenditure and lost productivity being borne by government health authorities and insurers – albeit much of it currently going into less fruitful directions. Clearly there will have to be 'a penny spent to save a pound'. The strategy gives a message of HOPE which is achievable for Australians, given the will to make changes and innovations in the directions outlined.

EXECUTIVE SUMMARY

The goal of the Pelvic Pain Steering Committee (Appendix V) is to ensure that this document reveals the extent of the pelvic pain problem in Australia, and provides pragmatic solutions for implementation and integration into women's health services.

From the outset of this project in May 2011, the magnitude of the health problem to be investigated was obvious. Pelvic pain disorders significantly disrupt quality of life and cause huge societal and financial burdens for a large percentage of our population. Pelvic pain in women is one of the last taboos of modern society. Its stigma permeates every aspect of her care from her parents' perception of their daughter's complaints, through the lack of integrated health services to the absence of pelvic pain as a worthwhile subject for clinical research.

As an example, endometriosis is one of the more common conditions associated with persistent pelvic pain. It is estimated to affect 176 million women worldwide in the 15 – 49 age group, which outnumbers the number of people in that age category affected by breast cancer, prostate cancer, diabetes I and II and AIDS. There is significant disruption to quality of life and major downstream problems for individuals, families, communities, health and welfare services and facilities and work-place productivity. The extent of the problem escalates dramatically if data from other pelvic pain-related conditions are included. Delays in early intervention and diagnosis create unnecessary far-reaching problems. Current services are at best fragmentary and piecemeal, and there is a large gap between best evidence and practice. The gap is emphasised further in the Australian Government's Health Policies and Strategies, which omit pelvic pain from the health plan.

There is, however, clear opportunity for recognition and inclusion of these conditions across all aspects of Australian Health Policies and Strategies, and the *National Pain Strategy* arising from the Pain Summit of 2010.¹

Early intervention, public education and effective therapy have the potential to eliminate or mitigate pain, returning women to years of personal and professional functionality. There is economic and community good to be gained per capita of population by investing in improved services. While only a snapshot of the magnitude of the health issue before us, this report amalgamates international data, government policies, experiences of health professionals, experiences of women and girls with pelvic pain and patient case histories. The Australian Government has made a commitment to Australian women to ensure a sustainable, high quality health system, which is responsive to all women now and in the future with a clear focus on illness prevention and health promotion as part of the *National Women's Health* policy.

Addressing pelvic pain must be a cornerstone of that commitment.

The purpose of this report is to identify the issues in diagnosis and management of pelvic pain, and to provide some solutions to influence the future health outcomes for Australian women and girls.

Working with Government, Medical Colleges, affiliated organisations, societies, faculties and those affected by pelvic pain conditions can assist in the implementation of the recommendations that will guarantee benefits to individuals, the business sector, and society at large. The recommendations have been proposed after strong input from women and girls with these conditions. This has been obtained through the 25 years experience of patient advocacy organisation Endometriosis New Zealand, Australian womens' case histories, and current Australian and New Zealand social networking comments.

This report has been organised into four parts:

Part One provides an overview of the problem, and defines pain and the goals of the project.

Part Two reflects the need for change; reviews existing health policies; identifies relevant aspects to pelvic pain and presents results from the advisory and patient groups which identify the barriers in providing and accessing care. There is a short section on services and organisations currently available.

Part Three recommends that it is accepted that pelvic pain is common and requires inclusion in stakeholders health policies, strategies and programs. We further recommend a series of measures to improve education, services, research and training (page 39).

Part Four concludes.

The appendices describe services currently available in New Zealand as an example of a multi-functioning non-government organisation, case study vignettes, social networking comments by affected girls and women, currently available international guidelines (from Part Two) and tables of economic data.

We gratefully acknowledge those who contributed to the project in an advisory capacity and those patients who kindly offered their stories as case studies (Appendix II, page 58). The appendices also include a brief biography of the Pelvic Pain Steering Committee and lists the Advisory Group.

We submit the *Pelvic Pain report* in the hope that our efforts will expedite recognition of the pelvic pain problem and ensure acceptance of the recommendations in order to facilitate change.

PART ONE

BACKGROUND AND PROCESS

A Pelvic Pain Steering Committee (Appendix V, page 67) was formed in May 2011 to investigate pelvic pain from an Australian perspective. The purpose was to begin the process of improving the health, wellbeing and productivity of women and girls by undertaking a report to define conditions causing pelvic pain, identify the related health issues, and articulate recommendations for action.

The *National Pain Strategy* and the Department of Health and Ageing's (DOHA) reports, policies and strategies provide the fundamental blueprint for integrating and implementing recommendations.

The project came about as a response to emerging national and international knowledge on pain and the heavy burden it imposes on individuals and society. An exploratory report to focus on this health issue within the pain spectrum had some urgency following the development of the *National Pain Strategy* in 2010. Empirical research on the prevalence of pelvic pain conditions and their impact on Australian women and girls was vague, and pelvic pain is largely unexplored compared to other painful health conditions. It was therefore appropriate that the Steering Committee combine their expertise and interest to highlight this as a health priority.

The project sought answers to the following questions:

1. Is pelvic pain a serious health issue in Australia?
2. Are current services for women with pelvic pain easily accessible?
3. Can pelvic pain be managed in a more cost effective way to improve access to pelvic pain health services throughout Australia, including regional and remote areas?
4. How can current services for women with pelvic pain be enhanced?
5. In what way can medical treatment and management be improved?
6. Are health care providers sufficiently resourced to cope with women who have pelvic pain?
7. How can existing strategies be utilised more effectively?
8. What are the key research priorities?
9. Who takes responsibility, and how can Medical Colleges, Consumer Organisations, Government and other stakeholders implement a National Pelvic Pain Strategy?

These questions underpinned the development of GOALS for the project (page 16) with the results reflected in the recommendations on page 39.

Advisors to the project (Appendix V, page 67) are practicing health professionals in the areas of gynaecology, pain medicine, physiotherapy, nutrition, general practice, indigenous health and research. They were consulted in small focus groups or through individual interviews. Their views and opinions

are combined in Part Two of this report. They do not represent the official policy of any specialist medical college, health body or organisation, but they do represent the considered thoughts of an experienced group of professionals. The advisors have not been involved in preparing this report. The Pelvic Pain Steering Committee recognise the importance of gastroenterology, psychology and paediatrics in this area though the timeframe did not allow for interviews with practitioners from these health disciplines.

The women and girls whose case studies are reflected in this report were interviewed individually. They gave permission for their case studies to be used and their personal stories and experiences of using the Australian health services are reflected in the results on page 58. Their patient history vignettes are included in Appendix II, page 58.

Australian and New Zealand women and girls have shared their experiences with pelvic pain on the Endometriosis New Zealand social network sites. Such comments were captured during May – July 2011 and are included in APPENDIX II, page 58.

WHAT'S IN A NAME?

At the outset of the project we knew that *just one* cause of pelvic pain, the condition called endometriosis, is estimated to affect 176 million women in the 15 – 49 age group worldwide; or 1 in 10 women.^{2,3} In that age group it is estimated that the incidence outnumbers those with breast cancer, prostate cancer, diabetes I and II and AIDS. The economic and societal effects of that number are staggering, as reflected in the title of this report. While endometriosis may be the most common cause of pelvic pain, and the condition for which we have the most data, the total cost from all causes of pelvic pain to the health system and our community is likely to be substantially higher than the estimate this report describes.

THE \$6B (SIX BILLION DOLLAR) woman refers to the estimated direct cost per annum of medical and surgical treatments for women with endometriosis in Australia, based on current data estimating 1 in 10 women. This figure does not include other conditions causing pelvic pain, indirect costs or adolescent girls.

The \$600M (SIX HUNDRED MILLION DOLLAR) girl similarly represents the estimated direct cost per annum of medical and surgical treatments for adolescent girls with endometriosis in Australia, or \$12,000/girl. An additional \$600M is spent on indirect costs per adolescent girl, including parents taking leave from work (over 50% of parents take over two months off work every year to look after their child or adolescents with chronic pain),^{5,6} other therapies and medications, and disability pensions. The figures are conservative and are based on the best available evidence.^{1,5}

Using epidemiological data from the University of Sydney Pain Management Research Institute, Access Economics produced the MBF Foundation report *The High Price of Pain*.⁷ It concluded that in 2007 alone, the cost of chronic pain in Australia was \$34.3 billion, or \$10,847/person/year.¹ Data from Australia and comparable international communities further confirm the costs of pelvic pain:

- In Australia (and around the world): endometriosis alone causes afflicted women to lose 11 working hours/woman/week in absenteeism (absence from work due to pain) and presenteeism (working less effectively due to pain)
- In Ireland, USA, UK, and Italy: the average extra cost/week/woman to the employer is \$200-\$250/week in absenteeism and presenteeism (Appendix IV, page 66, figure 1)
- Globally: companies suffer a \$2 trillion loss year in absenteeism alone, due to chronic disease (World Health Organisation)

The above data suggests that failure to take pelvic pain in adolescent females seriously, and failing to provide appropriate resources for adult females, risks the cost compounding exponentially in later years. The impact significantly disrupts quality of life and causes major downstream problems for individuals, families, communities, health and welfare costs and productivity.^{2,8,9,10}

EXISTING INFORMATION

This report uses endometriosis as a clinical reference point because more data is available for this condition, which is often a chronic disease. Endometriosis remains under reported, poorly understood, poorly treated, and causes a major economic and personal burden. While not all cases of pelvic pain are caused by endometriosis, and not all patients with endometriosis develop chronic pain, the data on this disease alone provides a compelling case for a new, directed, and organised approach to pelvic pain in general.

At the outset of the project, we knew the estimated prevalence and cost to society of endometriosis. Additional international data reveals that:

- endometriosis typically begins in adolescence^{11,12,13}
- women delay consulting a doctor for years before presenting with symptoms¹⁰
- there is a diagnostic delay of 8+ years from first presentation of symptoms^{2,10,14}
- women seek GP advice many times before a referral to a specialist is recommended¹⁰
- women will have been prescribed drugs ranging from non-steroidal anti-inflammatory drugs (NSAIDS) and pain relief to oral contraceptives^{2,8,10,15}
- women may have been misdiagnosed¹⁰
- women may have undergone unnecessary and expensive investigations¹⁶
- women may have not had the desired outcome from surgery¹⁷
- women may not have been believed or listened to¹⁷⁻¹⁸
- women may have had their hopes of conceiving dashed or delayed^{17,18}
- women frequently experience negative impact in relationships^{2,8,9,17,18}
- women have experienced a raft of 'hit and miss' treatments^{10,17,18,19}
- girls are at risk if there is a family history of the condition^{3,8,20}

Conditions associated with pelvic pain including endometriosis can no longer be ignored.

DEFINING PELVIC PAIN

The International Association for the Study of Pain (IASP) defines pain as “... *An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage*”.

Acute pain is defined as “*Pain of recent onset and probable limited duration. It usually has an identifiable temporal and causal relationship to injury or disease*”.²¹

Chronic Pain is defined as “*Pain that lasts for more than three months*”.²² Like all chronic pain, chronic pelvic pain can be caused by a treatable underlying condition. However it may also be a chronic disease entity, arising from a complex range of physical, psychological and environmental factors which need to be assessed and managed.^{1(appendix 1)}

Pelvic Pain is defined as ‘*abdominal pain occurring below the level of the umbilicus*’. It may or may not be associated with menstrual periods. Non-gynaecological causes of pelvic pain may be related to the digestive system, urinary system, musculoskeletal structures, nervous system of the pelvis or central nervous system. There is a strong association between persistent pelvic pain and psychosocial wellbeing.

Many conditions are associated with pelvic pain, although other factors may be involved in the patients’ experience of pain. These conditions include but are not limited to:

- endometriosis
- adenomyosis
- pudendal neuralgia
- painful bladder syndrome
- irritable bowel syndrome
- pelvic floor pain and dysfunction
- pelvic inflammatory disease (PID)
- vulvodynia
- inflammation
- proctalgia fugax
- pelvic adhesions
- urethral syndrome
- ovarian cyst pathology
- recurrent dysmenorrhoea
- post-surgical neuralgia
- neuropathic pain
- pelvic congestion syndrome
- post-trauma pain and cancer survivor pain

This report does not include pelvic cancers or pain associated with pelvic cancer. It does however include those cancer survivors with persistent pelvic pain.

This report recognises that in any individual pelvic pain can include several pathologies, including those that are undiagnosed.

VISIONS AND GOALS

This section describes the vision and goals for this report, and related salient points from each of the following organisations:

- Australian Government Department of Health and Ageing
- Royal Australian and New Zealand College of Obstetricians and Gynaecologists
- Faculty of Pain Medicine
- Painaustralia and the National Pain Strategy

THE PELVIC PAIN REPORT

Vision

To improve the quality of life for women and girls with conditions causing pelvic pain and to minimise the economic and personal burden on individuals and society.

Goals

- Goal 1:** To raise the profile of pelvic pain as a serious health issue in Australia
- Goal 2:** To promote prevention through early intervention and education
- Goal 3:** To improve access to pelvic pain health services
- Goal 4:** To educate health care providers and the community
- Goal 5:** To improve the diagnosis and treatment of women suffering from pelvic pain
- Goal 6:** To reduce downstream fiscal and personal health costs
- Goal 7:** To work with medical Colleges and Government to promote Fellowship Training
- Goal 8:** To integrate the project into the National Pain Strategy and the Department of Health and Ageing strategies with measurable and evaluative outcomes
- Goal 9:** To work alongside the Medical Colleges, affiliated organisations and Government, and
- Goal 10:** To foster research into pelvic pain

The AUSTRALIAN GOVERNMENT DEPARTMENT OF HEALTH AND AGEING (DOHA)

Of particular relevance to this project are the Australian Government's strategies relating to Women's Health. Other relevant strategies such as Diseases and Conditions; Chronic Conditions; Young People in Australia; Indigenous Australians; Young Australians; and Rural and Remote are discussed in more detail in Part Two.

The *National Women's Health Policy 2010* states "The Government aims to continue to improve the health and wellbeing of all women in Australia, especially those at greatest risk for poor health." It states it will do this by:

- using knowledge and information to deliver better services
- using integrated funding to deliver more effective services
- driving the system with the experience of the customer

Furthermore, the five goals of the *National Women's Health Policy* are to:

- highlight the significance of gender as a key determinant of women's health and wellbeing
- acknowledge that women's health needs differ according to their life stage
- prioritise the needs of women with the highest risk of poor health
- ensure the health system is responsive to all women, with a clear focus on illness, disease prevention and health promotion
- support effective and collaborative research, data collection, monitoring, evaluation and knowledge transfer to advance the evidence base on women's health

The ROYAL AUSTRALIAN AND NEW ZEALAND COLLEGE OF OBSTETRICIANS AND GYNAECOLOGISTS (RANZCOG)

The Pelvic Pain Report believes that Pelvic Pain is central to gynaecological practice, and that Gynaecologists are central to the management of conditions causing pelvic pain. The vision, mission, motto and work of the RANZCOG are acknowledged and described below.

Vision

The RANZCOG will pursue excellence in the delivery of health care to women throughout their lives.

Mission

The RANZCOG will achieve its Vision by innovative training, accreditation and continuing education supported by active assessment of the effectiveness of those programs.

The College will actively support and communicate with fellows, members and trainees in order to ensure that they are capable, physically, psychologically and professionally, of providing the highest standards of care.

The College will support research into women's health and will act as an advocate for women's health care, forging productive relationships with individuals, the community and professional organisations both locally and internationally.

Motto

'Excellence in women's health'

The FACULTY OF PAIN MEDICINE (FPM)

The Faculty of Pain Medicine is a Faculty of the Australian and New Zealand College of Anaesthetists (ANZCA) incorporating multi-disciplinary representation from the Royal Australasian College of Physicians (RACP), Royal Australasian College of Surgeons (RACS), Royal Australia and New Zealand College of Psychiatrists (RANZCP) and the Australasian Faculty of Rehabilitation Medicine RACP (AFRM RACP).

The Pelvic Pain Report believes that pain is central to the practice of pain medicine and pain specialists are central to the management of conditions causing pain. The vision, mission and work of the Faculty of Pain Medicine are acknowledged and described below.

Mission

The mission of the College is "to serve the community by fostering safety and quality patient care in anaesthesia, intensive care and pain medicine".

Goals

- Goal 1:** To promote professional standards and patient safety in anaesthesia, intensive care and pain management
- Goal 2:** To promote education in anaesthesia, intensive care and pain management
- Goal 3:** To advance the science and practice of anaesthesia, intensive care and pain management

PAINAUSTRALIA and the NATIONAL PAIN STRATEGY 2010

Relevant to this project are the mission and goals as agreed by the National Pain Summit 2010.

Vision

To improve quality of life for people with pain and their families, and to minimise the burden of pain on individuals and the community.

Goals

- Goal 1:** people in pain as a national health priority
- Goal 2:** knowledgeable, empowered and supported consumers
- Goal 3:** skilled professionals and best-practice evidence based care
- Goal 4:** access to interdisciplinary care at all levels
- Goal 5:** quality improvement and evaluation
- Goal 6:** research

The Painaustralia Business Plan 2011-12 addresses key performance areas and priority strategies also relevant to the Pelvic Pain project and this report.

The Pelvic Pain Report endorses the visions and goals of all these organisations.

PART TWO

THE CASE FOR CHANGE

Perhaps the biggest conundrum is that while chronic and complex health conditions are a high Government priority, one of the most prevalent conditions affecting women and girls in their formative and productive years is consistently overlooked in practice. In fact, pelvic pain conditions, despite creating major fiscal and human burdens, are not acknowledged or included in the relevant Australian Government's policies and reports on:

- Women's Health
- Diseases and Conditions
- Chronic Conditions
- Young People in Australia
- Indigenous Australians
- Rural and Remote

Part two of this report:

- presents the major financial and human burdens which support the case for change
- examines these policies and reports further, identifying whether conditions causing pelvic pain are reflected in policy and if not, considers those policies which have scope for inclusion
- presents the current project results from the advisory and patient groups
- identifies existing treatment guidelines for endometriosis: interdisciplinary services, Medicare Locals and Pelvic Pain Organisations in Australia

The financial burden

The High Price of Pain November 2007 report estimated that applying evidence-based treatments could halve the cost of chronic pain to the Australian economy – a saving of \$17 billion per annum.¹ With an estimated 550,000 women and girls with endometriosis in Australia, the cost for this condition for adult women alone is \$6.6 billion; or conversely the potential saving is \$3.3 billion. These figures would undoubtedly be higher if those young adolescent women with endometriosis and other conditions causing pelvic pain were included.¹ Also excluded are the indirect costs associated with disability and unemployment benefits, complementary medicine and therapies, and the costs of downstream infertility. Finally, the price for missed opportunities in life is incalculable.

Quality of life and economic productivity are acknowledged in the Australian Government's Health Policies and Strategies, but little attention is given to solutions and improving outcomes.

Yet, endometriosis, one of the leading causes of pelvic pain, costs the Australian Government billions in productivity losses alone. According to the *National Pain Strategy*, 55% of the total cost of chronic pain is borne by the individual concerned; the Federal Government bears 22%; the State and Territory Governments 5%, employers 5%; family and friends 3% and Society 10%.¹

Studies have shown that lost productivity in women with endometriosis is equivalent to 11 working hours per woman per week through absenteeism and presenteeism.² Endometriosis and conditions causing pelvic pain impose a substantial economic burden on society beginning with the onset of symptoms; spanning the typically delayed diagnosis, costly diagnostic testing, medical, and surgical treatments; and including the indirect costs associated with quality of life and productivity.^{2,5,9,14,15,18}

The human burden

Endometriosis is the most common condition among adolescent girls with chronic pelvic pain.^{11,12} The burden of endometriosis in the adolescent population is considerably under-appreciated and pain in children and adolescents is frequently under-treated.^{11,12,13,15,20} The impact of endometriosis in this population has not been widely studied. Yet the need for long-term management and interventions for this population typically persists into the childbearing years and beyond.

“From a woman’s perspective, endometriosis is a disease surrounded by taboos, myths, delayed diagnosis, hit-and-miss treatments, and a lack of awareness, overlaid on a wide variety of symptoms that embody a stubborn, frustrating and, for many, painfully chronic condition. It affects them *during the prime of their lives and through no personal failing in lifestyle choice*. Their physical, mental and social well-being is impacted by the disease, potentially affecting their ability to finish an education and maintain a career, with effect on their relationships, social activities, and fertility.”⁴

DEPARTMENT OF HEALTH AND AGEING POLICIES

The following section presents the six aforementioned Department of Health and Ageing policies, discusses pelvic pain in relation to these policies and outlines the current existing programs and their mandates.

Women's health

Government's Policies on Women's Health are presented on page 16. The five goals of these policies address maternal health, reproductive and sexual health, fertility and mental health, violence against women, and economic health and well-being. However, there was no mention of menstrual disorders or menstrual dysfunction.

Conditions causing pelvic pain underpin many elements of dysfunction in these areas.

The only acknowledgement identified was found on the DOHA Women's Health website which includes consumer information on menstruation, gynaecological conditions and disorders.²³

The DOHA website acknowledged endometriosis as a health issue affecting 10% of Australian women. As such, it affects the same percentage of Australians as does asthma, and yet no formal policies to address this and other chronic pelvic pain disorders have been developed.²⁴

Indeed, conditions causing pelvic pain other than endometriosis, add to the silent epidemic. Adding to the number of chronic pelvic pain sufferers are many women who survive cancer and may be left with debilitating, unresolved pain as a result of treatment. (Acute pelvic cancers are excluded from our study populations).

Pelvic Inflammatory Disease (PID) is an additional potential pathway to chronic pelvic pain conditions. Acute PID should prompt linkage to Sexually Transmitted Infection (STI) risk-reduction strategies, to prevent adverse outcomes.²⁵ Targeting adolescent education is a high priority to avoid long term chronic pelvic pain in women as a result of PID.

A common element of pelvic pain syndromes is dyspareunia (painful sexual intercourse). Sexual dysfunction has been linked not only to depression but also marital breakdown, which in turn has adverse effects on workplace productivity and home life.

Workplace absenteeism because of menstruation recently created unprecedented furore in New Zealand. Chief Executive of the Employers and Manufacturers Association NZ, Alasdair Thompson, observed that women in the workplace had more leave than men because of 'monthly sickness'. Although Mr Thompson was subsequently dismissed, his statement illustrates both the difficulties women encounter accessing appropriate care, and the size of the gap which exists in the public knowledge base.²⁶ A study in Sydney which quantified the effect of chronic pain in the workplace,

added together the lost work days and 'reduced-effectiveness' work days to find an average total of 16.4 lost work day equivalents over a six month period in this population. This was three times higher than the average lost work days alone.¹ Presenteeism and absenteeism were major findings in the Global Study on Women's Health (GSWH) (Appendix IV, page 66, figure 1).²

The GSWH also showed that non-work related activities, such as housework, exercising, studying, shopping, childcare and community volunteerism were significantly impaired by the painful symptoms of endometriosis.²

Healthy ageing may also be adversely affected. Although many chronic pelvic pain syndromes begin in adolescence and are experienced during the menstrual years, the consequent distortion of anatomy and long term suffering can affect those with the condition long after menopause.

Key issues which can inhibit some women's access to health care correspond with barriers acknowledged in our case study group and include inequality in care, discrimination, the chronic nature of symptoms, navigating the health system, benefit reliance and pre-conceived judgements. Women's stories relayed the experience of social stigmas during the interview process (Appendix II, page 58). Interestingly, 'stigma' or being 'written off as psychologically defective' was high on the list of consumer feedback in the interim report of the *National Pain Strategy*.¹ Recent research acknowledges that women may delay seeking help because of the "discrediting" nature of menstrual irregularities, the risk of stigmatisation and frustrations with treatments received to date.^{8,10,14,15,18}

Government has identified the need to detect and treat any disease in its early stages. Through research and consultation, a series of evidence-based health priorities have been identified by Government that represent the major challenges associated with death and burden of disease for women in the next 20 years.

These health priority areas are:

- prevention of chronic disease and control of risk factors
- mental health and wellbeing
- sexual and reproductive health

Conditions causing pelvic pain, while not recognised as 'priority' conditions in DOHA's policy on Women's Health, align with these three priority areas identified by Government and are reflected in the recommendations in this report.

Diseases and Conditions

The Australian Government is committed to "better health and active ageing for all Australians". A range of conditions and diseases are listed on the DOHA website and some of the new initiatives and programs to address the priority diseases and conditions effecting Australian citizens are profiled.

Our literature review did not uncover endometriosis or conditions causing pelvic pain in the list of diseases or conditions apart from consumer information on endometriosis as explained in “Women’s Health” on page 17 of this report. Pelvic Pain conditions are often referred to as diseases (as in the case of endometriosis) or conditions.

As reported by Australia’s National Agency for Health and Welfare, the burden of disease and injury is measured in Australia using the ‘disability-adjusted life year’ (DALY). The DALY measures the years of life lost due to premature death coupled with years of ‘healthy’ life lost due to disability. One DALY is equivalent to one lost year of healthy life. The total burden of disease and injury in Australia in 2003 was 2.63 million DALYs. Women accounted for 1.3 million DALYs.

Beyond the disability resulting from the incapacitation of pain, pelvic pain conditions can cause significant secondary mental health issues. In 2007, 43% of all Australian women (3.5 million) had experienced mental illness at some time in their lives, and at least one in five experienced issues between the ages of 16 and 54 years. Anxiety and depression are the leading burden of mental ill-health for women. While the literature review did not identify causative pathology, there is a link between acute and chronic pain and mental health issues.²⁵

Government recognises that diseases and conditions contribute to workplace absenteeism and has introduced the *Healthy Workers initiative* (\$294.4 million from 2011–12 to 2014–15) which provides funding to support implementation of healthy lifestyle programs in workplaces. The states and territories facilitate the implementation of the program and the Commonwealth provides national-level soft infrastructure support.

The introduction of a workplace wellness program to improve the health and wellbeing of women which covers issues affecting women today relevant to the workplace and home is a key recommendation in this report. An example of such is that operated by Endometriosis New Zealand. (Appendix 1, page 53)

Chronic Conditions

The following quote is taken from the *Australian National Chronic Disease Strategy*. (NHPAC) (2006):

“The world health organisation warns that the global burden of chronic disease is increasing rapidly. In Australia, the burden of chronic disease and its consequent effect on disability and death is growing in line with this trend.

Australia’s health system must be able to respond in an appropriate and cost effective way to this challenge. Failure to prevent, detect and treat chronic disease at an optimal stage in its course impacts on affected individuals and their families and carers in terms of pain and suffering and on the whole Australian community in productivity losses and high health care costs.

Accordingly effective health care management of chronic disease is a key policy objective of the Australian and all state and territory health systems.

Chronic diseases are also associated with high use of health care services, contributing to major funding pressures in Australian health care that are expected to rise over coming decades as prevalence increases.”²⁹

The Australian Government acknowledges the “*increasing prevalence of chronic disease and the enormous associated personal, social and economic cost to the community*”. To address this, a wide range of programs and initiatives to provide assistance in the area of chronic disease have been initiated, including:

- programs to increase access to care and medicines
- initiatives to promote best-practice care
- risk factor prevention and management
- research programs
- programs providing support to people with specific chronic diseases with the aim of reducing the overall burden in these areas

However, conditions causing pelvic pain are not currently identified in policy.

To address the needs of people with chronic pain, Eight National Health Priority areas have been identified which contribute significantly to the burden of illness and injury, and which have potential for health gains and reduction in the burden of disease.

However, conditions causing pelvic pain are not included as a National Health Priority.

The *National Pain Strategy* revealed that less than 10% of people with chronic non-cancer pain gain access to effective care. Yet, we know that effective care *is* available for chronic pain sufferers. Existing treatments have the potential to help 80% of people with chronic pain, and 90% of those with pain following surgery or trauma. Our literature review identified several government initiatives designed to help patients address lifestyle risk factors for chronic disease that might be adapted for chronic pelvic pain.

For example, the *Lifescrpts* plan provides general practice with evidence based tools and skills to help patients modify their lifestyle. The *Prevention of Chronic Diseases through the Control of Risk Factors* plan targets chronic disease and risk factors and encourages a clearer understanding of the context of women’s lives, including the barriers that prevent women taking up healthier lifestyle behaviours. And in the specific area of chronic pain, workers’ compensation-funded cognitive-behavioural therapy programs such as *ADAPT* and *COPER*, associated with the Royal North Shore Pain Management Research Centre in Sydney and the Flinders Pain Management Unit in Adelaide respectively, are important evidence-based strategies which warrant consideration of support and replication on a wider scale.

Early intervention, education and effective treatment, addressing health issues in the acute phase are essential in reducing the likelihood of chronic, lifelong disability.^{21,30} This potentially improves the status of women, allows for improved quality of life and productivity and reduces the likelihood for women to rely on government benefit schemes.

Australia is well positioned to include pelvic pain in the list of health priorities so that women and girls can access appropriate health care and experience improved health outcomes.

Young People in Australia

The Australian *National Youth Health Information Framework* consists of three broad groups of indicators of youth health: health status and outcomes; risk and protective factors; and services and interventions. Within these three groups, a number of broad subgroups have been identified:

- The 'health status and outcomes' group with two subgroups: life expectancy and wellbeing; and mortality, morbidity and disability
- The 'risk and protective factors' group with five subgroups: environmental factors; socioeconomic factors; community capacity; health behaviours; and person-related factors
- The 'services and interventions' group which covers health programs, health promotion and intervention, health services to individuals, intersectoral services, community services and youth services

Period pain, pelvic pain, painful sex, endometriosis or menstrual disorders are not included in the report. "*Stomach pains*" are described as a "*possible additional indicator area*" and as "*psychosomatic symptoms.....thought to have an emotional rather than clinical origin*".

The second *National Report on the Health and Wellbeing of Young People in Australia* (2003) states that:

"Young people can be put at risk if they do not have the information, skills, support or access to health services to deal with problems they may encounter as they pass through adolescence."

The report provides an overview of the health status of young people with regard to chronic conditions; sexual and reproductive health; morbidity; health and wellbeing and disability. However, through this report, and the followup reports entitled *Young Australians: their Health and Wellbeing* (2007 and 2011) there is no mention of endometriosis, period pain or menstruation.

The report *Chronic Conditions in Young Australians* lists asthma, diabetes and cancers as key priority conditions, and factors such as obesity that contribute to this risk are described. The report presents clear evidence prioritising these conditions, yet the prevalence of endometriosis and pelvic pain data equals or surpasses other conditions given a high priority.³¹

Pelvic pain frequently affects young women, often from their early teens. However, paediatric pelvic pain is poorly researched in Australia, and associated health conditions such as endometriosis are frequently not considered in determining the cause of the pain or providing age-appropriate health interventions in this group. Internationally, chronic pain in adolescents is recognised as a significant problem. Data from studies of children and adolescents in the UK reveals that the most common group presenting with pain are 14 – 15 year old girls with undiagnosed abdominal pain and headaches. Our review did not indicate that pelvic pathology was considered as a contributing factor.^{1,5}

An Australian Capital Territory (ACT) study (2005) showed that 26% of young women aged between 16 and 18 years experienced significantly life-compromising menstrual pain requiring them to have regular time off school.³² Endometriosis New Zealand's (ENZ) teenage program in schools, known as 'me' was introduced in 1997 and supports the findings of the ACT study. After participating in the 'me' program, 29% of girls are aware that their menstrual symptoms and pain may not be normal. The program has positively influenced outcomes for girls and young women with pelvic pain. Though data is unpublished, increased trends in presentation of symptoms, intervention and early diagnosis are key outcomes. (Appendix IV, page 66, figure 2)

The National Health and Medical Research Council (NHMRC) recommends education programs that target primary prevention behaviours among young people. Given that endometriosis symptoms frequently begin in the teen years, and that these symptoms may be an early 'marker' for chronic pelvic pain, there is a clear need to inform, recognise pathology, and treat appropriately to avoid major downstream economic and personal losses in this group.

Government has initiated the *Early Intervention Services for Parents, Children and Young People* program which aims to support mental health promotion, prevention and early intervention for all children through universal evidence-based school and early childhood programs. Targeted programs are aimed at those children at highest risk of developing mental health problems, or with early signs, symptoms or diagnosed mental health problems. Currently this program does not include services for pelvic pain in children or adolescent females. The *Early Intervention Services for Parents, Children and Young People* program could be extended to help young people cope with pelvic pain from a mental health perspective.

The Department of Health and Ageing has funded, established and implemented a range of programs and strategies that address, or are relevant to, the health and wellbeing of young people. DOHA states that their programs are based on evidence and knowledge of the major health issues facing young people today. It would be advantageous if these strategies, programs and initiatives included conditions causing pelvic pain. The goals suggest they may be amenable for inclusion.

Indigenous Australians

The Department of Health and Ageing takes a whole of government approach to improving Aboriginal and Torres Strait Islander health. DOHA's vision for the future is: "health outcomes and health services for Aboriginal and Torres Strait Islander peoples equal to that of the general Australian community."³⁴

Conditions causing pelvic pain are not included as a health issue for Aboriginal and Torres Strait Islander women. In fact, data indicating the incidence of endometriosis and pelvic pain in Aboriginal and Torres Strait Island women are non-existent. However, it is likely that the true prevalence of endometriosis in indigenous Australian women is under reported owing to inadequate facilities, lack of presentation to health care services, and lack of providers with specialised skills for adequate assessment of the pelvis. Understanding the prevalence of endometriosis and pelvic pain conditions among Aboriginal women will be instrumental in proper management of this disease in indigenous Australians.³⁵

There is a high prevalence and incidence of gonorrhoea and chlamydia in Aboriginal people which increases with remoteness.³⁶ Much of this is asymptomatic in presentation. Women with recurrent PID are significantly more likely to report infertility and chronic pelvic pain long-term than are those without recurrent PID, according to a secondary analysis of the PEACH study.²⁵ There was also a lower quality of life among women with chronic pelvic pain following PID.^{25,37} Even when acute STIs are identified and treated, there are no follow-up programs available to address downstream infertility or chronic pelvic pain.^{37,38}

The Australian Government has introduced a new initiative *Closing the Gap* for Indigenous Australians (2011). The package aims to achieve a reduction in chronic disease by providing support to the health sector and better access to health care for Indigenous Australians. *Closing the Gap* identifies chronic diseases as a priority area but does not include pelvic pain conditions within the framework. Given the likelihood that conditions causing pelvic pain may develop as a result of STI's, it is essential to allow for appropriate treatment and follow up.

Access and equity strategies address the funding required to close the gap in Aboriginal and Islander Health in Far North Queensland.³⁹ *The Indigenous Chronic Disease Package* (ICDP) provides:

- funding for preventative health focusing on Aboriginal and Torres Strait Islander individuals, families and communities
- support and funding for more coordinated and patient-focused primary health care for Aboriginal and Torres Strait Islander people in both Aboriginal Community Controlled health services and mainstream general practice
- an expanded Indigenous health workforce

The new *Urban Specialist Outreach Assistance Program (USOAP)* is another initiative developed to contribute to better health outcomes for Aboriginal and Torres Strait Islander people by increasing access to medical specialist services. The program is funded through the federal government and the Department of Health and Ageing.

Neither the ICDP or USOAP initiatives mention the inclusion of chronic pelvic pain services but the goals of the programs suggest they are amenable for inclusion.

Rural and Remote

The Policy for rural and remote women's health services states that:

"All Australian women regardless of their geographic location, ethnicity, sexuality or financial resources have the right to universal access to basic health care that is high quality and responsive. However, some groups of women face significant barriers in accessing health care services and information. These groups can include Aboriginal and Torres Strait Islander women, culturally and linguistically diverse women, women with disabilities and women in same sex relationships. It is important that attempts are made to understand the needs of these groups in order to reduce the barriers in accessing services."

Government has introduced several programs for women in rural and remote Australia. However, pelvic pain conditions do not feature in these policies.

The *Rural Women's General Practice Service (RWGPS)* program aims to improve access to primary health care services in areas who currently have little or no access to a female GP, by facilitating the travel of female GPs to these communities.

The *Sexual Health Information Networking and Education SA (SHineSA)* organisation works in partnership with government, health, education and community agencies and communities to improve the sexual health and wellbeing of South Australians.

The *Rural Primary Health Services* program aims to improve access to a range of primary and allied health care services and activities for rural and remote communities. Primary health care services encompass active treatment through provision of allied health services, mental health services, screening programs, health promotion and preventative health activities.

The *Medical Specialist Outreach Assistance Program (MSOAP)* was established to improve access to medical specialist services for people living in rural and remote locations. The MSOAP complements medical specialist services provided by the Government and private providers by encouraging specialists to deliver outreach services to targeted areas of need in rural and remote Australia. The medical specialist disciplines supported include Obstetrics and Gynaecology, Sexual Health, Pain Medicine, Oncology and Psychiatry.

Australia is set up for rural and remote health services. However, refining the services provided to improve access to gynaecological care and assistance navigating the health system would improve outcomes for women from rural and remote areas.

CURRENT PROJECT RESULTS FROM THE ADVISORY AND PATIENT GROUPS

Health professionals, researchers and patients were consulted to articulate the issues and barriers faced when either providing or accessing pelvic pain services in Australia. The following sections list the outcomes from each of the interview groups.

1. Gynaecologists

- 1.1. Pelvic pain not recognised or validated as a distinct clinical entity
- 1.2. Lack of viable career structure for gynaecologists wishing to improve their skills managing pelvic pain therefore no incentives to manage chronic pelvic pain (CPP)
- 1.3. Lack of experience, education and training in pelvic and vulval conditions and pain management
- 1.4. Lack of national consistency in recognition, diagnosis, treatment and management of CPP
- 1.5. Insufficient number of highly skilled gynaecologists trained in advanced laparoscopic surgery and vulval disorders
- 1.6. Public health coding system for pelvic pain hinders data gathering, stifles accurate research and skews funding allocation requirements
- 1.7. Remuneration is based on patient throughput rather than the complexity of conditions with which patients present. A change in the Medicare rebate is required to overcome this barrier. There is currently no incentive to manage CPP patients efficiently and effectively because of the complex nature of these conditions
- 1.8. Waiting lists and triaging need urgent review. Many patients are missing out on basic 'duty of care' from public health providers. Patients face long waiting times eventually seeing a gynaecologist who has no sub-specialty capability.
- 1.9. Under-utilisation of public / private interface for tertiary referral
- 1.10. Disparity in service between public and private health care
- 1.11. Ineffective and repeat treatments
- 1.12. Clinical inertia
- 1.13. Dislocated use of inter-disciplinary services including pain management, psychology and physiotherapy health services
- 1.14. Reactive response to treatment and management
- 1.15. Patient pressure for repeat surgeries
- 1.16. Poor referral processes e.g. expiry system is cumbersome and costly and discourages patient follow up
- 1.17. Poor quality referrals
- 1.18. Patients have often missed out on a tier of care between GP and hospital referral
- 1.19. Service to CPP patients can't be delivered under the current 'case mixed' model
- 1.20. Tyranny of distance
- 1.21. Widespread prejudice across senior management in corporate and business Australia against women who have menstrual dysfunction

- 1.22. Societal misunderstanding and poor acknowledgement of these conditions result in workforce, community, relationship and personal failures

2. Non-Gynaecology Medical Specialists - Pain Specialists, Paediatric Pain Specialist, Nursing Specialist

- 2.1. Dichotomy of inequity for women's gynaecological health care services
- 2.2. Pelvic pain has associated stigma and is not legitimised
- 2.3. Referral processes are slow, unreliable and infrequent
- 2.4. Lack of training in conditions causing pelvic pain
- 2.5. Appropriate treatment is often inaccessible and not available
- 2.6. Expectation that patients have already had best practice gynaecological treatment
- 2.7. Lack of training within other disciplines
- 2.8. Funding streams dysfunctional e.g. Inequity in consultation times
- 2.9. Consultants are financially disadvantaged as longer consultations are required
- 2.10. Not recognised as priority conditions therefore under-resourced, under-funded, under-treated
- 2.11. Disbelief that conditions causing pelvic pain are common
- 2.12. Lack of training and recognition in paediatric pelvic pain
- 2.13. Lack of understanding about pelvic pain from patients, community, health professionals
- 2.14. Private pain. Rarely visible. Not talked about
- 2.15. Expectation that women will have to 'bear' pain
- 2.16. Not prioritised
- 2.17. Insufficient cohort working in the field

3. Researchers

- 3.1. Progress in basic and translational research will need cross discipline research and better integration
- 3.2. Lack of data on costs and impact of endometriosis and relative estimates for other diseases in Australia to justify research applications
- 3.3. Need for large sample collections with detailed information on disease diagnosis and progression
- 3.4. Low research dollar priority

4. General Practitioners

- 4.1. Lack of any guidelines or pathways
- 4.2. Lack of GP education for identifying symptoms for earlier intervention, management and referral
- 4.3. Lack of GP resource and ancillary services
- 4.4. Limited treatment options

- 4.5. Lack of awareness of available treatments
- 4.6. Ineffective and repeat treatments
- 4.7. Clinical inertia
- 4.8. Chronic pain patients are time consuming, difficult to schedule, difficult to treat
- 4.9. Geographic isolation
- 4.10. Current system lacks flexibility and opportunity to explore complex health issues
- 4.11. Mental health cuts will seriously compromise GP ability to provide patient care
 - 4.11.1. Item 2710 to be removed
 - 4.11.2. Current plan works well and is cost effective approach to service provision
- 4.12. Overcoming racial and religious stigma
- 4.13. Lack of specialist services especially in the public system
- 4.14. Patients normalise symptoms – non presenting
- 4.15. ‘Shame job’ – women feel ashamed of presenting with these symptoms
- 4.16. Women have an issue discussing symptoms with male doctors
- 4.17. Lack of private facilities to examine women
- 4.18. Aboriginal women are ashamed to be examined during the day or when there are men around
- 4.19. Lack of female chaperone’s to assist with patient examinations
- 4.20. Lack of knowledge and sensitivity about pelvic examinations (especially in women who are not sexually active)
- 4.21. GP fear of examining women
- 4.22. Lack of specialist services and long waiting time for referrals in public system

5. Physiotherapists

- 5.1. Pelvic Floor Physiotherapy - Lack of education for health professionals and poor training opportunities in pelvic pain. Training must include allied health professionals
- 5.2. Dislocated referral systems
- 5.3. Level of experience and expertise varies widely within this specialty
- 5.4. Lack of standardised education or specific qualification in CPP management for practitioners
- 5.5. The need for medicare cover for physiotherapy services
- 5.6. Disparity between public and private health services and many patients unable to access specific services
- 5.7. Diluted services for pelvic pain making it an ‘insignificant’ health issue
- 5.8. Challenging patient group to treat:
 - 5.8.1. Often suffered conditions for long periods
 - 5.8.2. Time consuming
 - 5.8.3. Frequently present with psychological and emotional consequences of pain
- 5.9. Rural women have long travelling distances
- 5.10. Poor public awareness

6. Dietician

- 6.1. Challenges in developing referral processes with other medical disciplines
- 6.2. Territorial referral processes hinder patient access to most appropriate dietitian
- 6.3. Lack of time and or interest from some GP's to source available services
- 6.4. Unnecessary anti-depressants or antibiotics prescribed as treatment option
- 6.5. Patients report having had their symptoms 'dismissed' by the GP or specialist
- 6.6. High cost precludes women affording dietetic services
- 6.7. Patients not always aware of funding options, therefore they exclude the option before even requesting a referral
- 6.8. Patients may have investigations and tests through the public services. Long waiting times and poor follow up
- 6.9. Patients often consulted a variety of other therapists who may have incorrectly diagnosed, used non-validated tests and prescribed medications or treatments without professional supervision
- 6.10. Referral network to other therapies and activities (e.g. hypnotherapy, exercise, lifestyle changes) are used but are generally under-utilised and haphazard across the disciplines

7. Women and girls with pelvic pain

- 7.1. Lack of awareness of services available
- 7.2. Lack of knowledge about the condition
- 7.3. Inequalities in accessing care because of:
 - 7.3.1. geographical location
 - 7.3.2. specialist assessment with appropriate referral
 - 7.3.3. discrimination / ethnic / social / age / socio-economic / financial
 - 7.3.4. language
- 7.4. Unacceptable delay in symptom recognition and diagnosis
- 7.5. Lack of inter-disciplinary services - mental, emotional, physical
- 7.6. Unacceptable variance in treatment management practices
- 7.7. Navigating health services to access care
- 7.8. CPP low priority in accessing basic public health care
- 7.9. Personal and public burdens and barriers (schools, workplace, financial, government)
- 7.10. Chronic debilitating and incapacitating symptoms with no visible solutions
- 7.11. Inequity of treatment available
- 7.12. Normalising symptoms and acceptance of menstrual and pelvic disorders
- 7.13. Daily function is so impaired that arranging medical care and trying to access appropriate services becomes overwhelming
- 7.14. Reliance on benefits - disability and unemployment
- 7.15. Symptoms interfere with productivity
- 7.16. Lack of prevention or identification of high risk factors

- 7.17. Pre-conceived judgments and prejudice from health professionals
- 7.18. Public stigmatisation of these conditions and the associated symptoms
- 7.19. Low expectation of service delivery and health care

EXISTING INTERNATIONAL TREATMENT GUIDELINES FOR ENDOMETRIOSIS

Worldwide, expert groups comprised of medical researchers and clinicians have issued guidelines for treatment of endometriosis. Some of these guidelines include the management of conditions causing pelvic pain. The majority of these groups are not government sponsored and include:

- European Society for Human Reproduction and Embryology (ESHRE)
- Royal College of Obstetricians and Gynaecologists (RCOG)
- American Society for Reproductive Medicine (ASRM) (Two Guidelines)
- Danish National institute of Health
- A study appraising existing international guidelines for the management of pelvic pain⁴⁰

A brief outline on each can be viewed in Appendix III on page 64.

INTERDISCIPLINARY SERVICES FOR PELVIC PAIN IN AUSTRALIA

Although the primary care and management of conditions causing pelvic pain is, and should remain, the role of the GP and gynaecologist, the currently available guidelines from the above listed organisations recognise the role of a multi-disciplinary approach.

Supporting the treatment of girls and young adolescent females may also include paediatric services.

INTERDISCIPLINARY PAIN CLINICS

Most large public hospitals in Australia have a pain management unit able to offer specialist assessment of the physical, psychological and environmental factors contributing to pain in individuals where pain is complex and for whom more generally available services have been insufficient.

However, women with pelvic pain also require assessment by a gynaecologist and pelvic physiotherapist experienced in the management of CPP. These services are not currently generally available in pain clinics.

Examples of interdisciplinary care are acknowledged in the National Pain Strategy¹ although none of these are specific to gynaecology and women's pelvic pain.

ALLIED HEALTH PROFESSIONALS

Services to reach women with associated symptoms e.g. those related to digestion and pelvic physiotherapy exist in most cities. Integrating these services is seen as a priority in reducing economic burden, improving the health and wellbeing of these patients and streamlining the patient journey.

MEDICARE LOCALS

This new initiative provides opportunities to improve the management of pain at a local level and arising from this - the opportunity to improve pain services nationally. Paediatricians and GP's are pivotal in recognising the presentation of these conditions and arranging appropriate care.

The Federal Government's primary health care reform launched nineteen Medicare Locals on 1 July, 2011 - the first of a total of sixty two to be formed nationally. The roll out of Medicare Locals is being led by the Australian General Practice Network. The reforms are designed to make it easier for patients to access the services they need within local communities.

PELVIC PAIN ORGANISATIONS IN AUSTRALIA

There is no national organisation providing services and programs for pelvic pain in Australia.

The Endometriosis Association (QLD) Inc. (QENDO) is a volunteer non-profit support group that provides education, information and support to women with endometriosis. Services include an informative website, endometriosis awareness week events, newsletter, community awareness, telephone counseling by volunteers and the opportunity for women to meet with others affected by the condition.

Endometriosis New Zealand (ENZ) is an organisation established 25 years ago operating many services and programs to meet the needs of all stakeholders. ENZ is a professional, board governed organisation offering schools, hospital and workplace programs, support and resources. It now addresses conditions causing pelvic pain in the course of its work. ENZ receives many pleas for help from Australian citizens but, as a Non-Government Organisation (NGO) and Registered Charitable Trust, it is resource restricted in the help it can provide to Australians but is amenable to assist in service provision. The article *Endometriosis New Zealand - a national organisation pivotal to facilitating the wellness of women* is included in Appendix 1 on page 53.⁴¹

SUMMARY OF PART TWO - THE CASE FOR CHANGE

The DOHA Policies and Strategies explained in Part Two reflect Government's health priorities and provide solutions to those conditions that have been identified. While pelvic pain conditions are not identified in the health policies recognised as being relevant to the health issue, there is opportunity for inclusion in these policies and scope to roll out services and programs through current Government initiatives.

Chronic Pelvic Pain patients generally present with a range of long-standing complex and challenging health issues. Part Two has described some of the barriers and issues faced by health care providers and patients. It has revealed opportunities for improving services and for linking existing networks to maximise health outcomes and it has examined models that could be expanded.

Health promotion and prevention, and effective specialised care and treatments are crucial steps in reducing the morbidity, health care expenditure and lost productivity associated with endometriosis and other conditions causing pelvic pain. The substantial economic burden accentuates the need for further research into cost-effective approaches for diagnosing and treating these conditions. It also identifies the urgent need for practical relief solutions.

The dislocated inter-disciplinary referral system was raised in all interviews as exemplified at a dedicated private pelvic floor physiotherapy clinic in Adelaide. Physiotherapists providing chronic pelvic pain services have advanced post-graduate training. There are a limited number of suitably qualified physiotherapists which means that quality services are difficult to access. Physiotherapy services are available in some well-established pain clinics. However, the services offered in these clinics may not be appropriate for those with pelvic and perineal pain.

Patients at the private physiotherapy clinic interviewed are women aged from seventeen through to post-menopause, who require specific treatment for pelvic pain, sexual dysfunction, menopause-related symptoms and post-surgical pain. The clinic also sees men with chronic pelvic pain. Interdisciplinary referrals (per annum) to this clinic for management of pelvic pain are via one gynaecologist, three GP's, zero pain specialists and one sexual therapist.

The majority of GPs refer their patients to these physiotherapists for irritable bowel symptoms, fatigue or lower back pain without first entertaining a diagnosis of endometriosis or other pelvic pain condition, so patients arrive undiagnosed and therefore under-evaluated, despite these being symptoms commonly associated with pelvic pathology which are often worse with menstruation.

Several advisors felt that the lack of an organised approach to CPP diagnosis and management reflects societal biases and understates women's contribution to the growth and development of our society, present and future. It was strongly believed that bringing the conversation into the open and implementing evidence based solutions would improve outcomes and ensure the largest potential workforce is available in Australia to meet the challenges and demand for future growth. At present

there are inadequate resources, financial incentives, and physician training to deal with the very complex and demanding issues surrounding chronic pelvic pain.

Australia is world renowned for endometriosis research. The Queensland Institute of Medical Research in research partnership with Oxford and Harvard Universities has been conducting a study into the genetic link of endometriosis since the early 1990s. Significant recent progress confirming a genetic contribution to endometriosis risk and the first markers associated with disease have been identified. Further work is needed to identify the specific genes involved and translate basic knowledge to better diagnostic methods and treatments.

The Monash Institute of Medical Research and Prince Henry Institute (both of Melbourne); the Women's Health and Research Institute of Australia and the University of Sydney (both of Sydney) and the Endometriosis Research Centre, University of Adelaide (Adelaide) are recognised worldwide for contributions in endometriosis research. Three key Australian researchers contributed as authors to the international standards outlined in *Priorities for Endometriosis Research: Recommendations from an International Consensus Workshop*.³

While the continuance of this research is vital to the outcomes for Australian women, future research is funding reliant. The magnitude of endometriosis and other conditions causing pelvic pain is overlooked in terms of the national spend of research dollars. The size of the problem grossly outweighs current research endeavours and associated funding.

Current patient and consumer information such as those produced by RANZCOG (*Chronic Pelvic Pain, a Guide for Women* and other resources) and the range of resources produced by Endometriosis New Zealand are excellent but have limited outreach.

Part Two has exposed major gaps in medical, consumer and community knowledge and service delivery.

Five key issues of concern emerged in the feedback from the advisory group and patients, which are reflected in the recommendations. These are:

- Health promotion and prevention
- Funding
- Quality of Service
- Ancillary services
- Time

There is an urgent need for change and inclusion of pelvic pain in Government's Health Policies to improve efficacy.

PART THREE

RECOMMENDATIONS

Key goals to progress the Pelvic Pain Project vision have been recognised in Parts One and Two. These goals integrate seamlessly with those of the:

- National Pain Strategy
- Australian Government DOHA policies, strategies and programs

The recommendations in this report are guided by the Australian Government's health statements that advise:

- using knowledge and information to deliver better services
- using integrated funding to deliver more effective services
- driving the system with the experience of the customer

With regard to pelvic pain and following the investigations of this report, the Steering Committee believe that:

- ✓ *We do* have the knowledge and information to deliver better services
- ✓ *We can* integrate funding to deliver more effective services
- ✓ *We are* driving the system with the experience of the customer

The following recommendations allow implementation of pragmatic solutions in a phased rollout for integration into women's health services nationwide. They have been made as a result of collaborative communication with associated stakeholders and focus on health promotion, prevention and research. Where possible the recommendations integrate with but are not limited to existing government strategies (indicated in italics).

The recommendations are as follows:

- 1. That it is accepted by all stakeholders that conditions causing pelvic pain are common** and require inclusion in the Australian Government Department of Health and Ageing Health Policies, Strategies and Programs.
- 2. That further assessment of how effective change can be achieved is urgently required.** This will require the appointment of personnel in positions of authority to establish, organise and develop evaluative measures for each program initiated. The authors of this report are willing to provide their expertise.

3. That the need for early diagnosis and intervention in women and girls with pelvic pain be recognised. Streamlining and enhancement of community care in this area would be facilitated by:

3.1. The provision of opportunities for up-skilling of GPs and community health providers in pelvic pain through targeted educational seminars and existing initiatives such as Medicare Locals.

3.2. That a stand-alone website for pelvic pain be developed as a gateway to information, training, services and programs utilising the NBN to reach Australians in metropolitan, regional, rural and remote locations. (Australian Government Department of Broadband, Communication and the Digital Economy).⁴² It is recommended that the existing domain name *Pelvic Pain Australia* be utilised for this purpose.

3.3. Recognition that effective care requires both a need to diagnose underlying pathology, and identify other factors that may contribute to chronic pain.

4. That public education programs be established to promote early presentation to health professionals, early diagnosis and intervention. These programs should include:

4.1. Workplace wellness programs to address absenteeism, low productivity concerns and the stigma of pelvic pain. This recommendation aligns with *Industry Partnership Programs*, the *Healthy Workers Program* and the following DOHA policies:

- a. *Women's Health*
- b. *Diseases and Conditions (Prevention of chronic disease and control of risk factors)*
- c. *Chronic Conditions (Burden of disease and Injury)*

4.2. Secondary school education programs to address awareness of the early signs of pelvic pain and allow early recognition and intervention where appropriate. This recommendation aligns with the following DOHA initiatives:

- a. *Young Australians*
- b. *Disabilities and Young Australians*
- c. *Early Intervention Services for Parents, Children and Young People*
- d. *Prevention of Chronic Disease and Control of Risk Factors (The Measure Up campaign)*
- e. *Chronic disease research programs*
- f. *As recommended in the High Price of Pain report (Nov 2007)*

4.3. Community education programs to avoid 'normalisation' of pelvic pain, decrease the stigma associated with pelvic pain, and encourage the families of women with pelvic pain to assist affected women access appropriate care.

This recommendation is aligned but not limited to the following DOHA policy:

a. Rural Primary Health Care Services

- 4.4. **Online services** which are age-appropriate for both teens and adult women to facilitate education and navigation through existing services
- 4.5. **Services that address the specific needs of indigenous communities** and culturally diverse communities
- 4.6. **Monitoring and evaluation of new programs as an integral part of strategy planning**

Such promotion may be expected to result in the increased presentation by women and girls to health care providers with these conditions, and strategies to effectively manage these patients will be required to avoid further stress on current services. For all services, we recommend that outcome measures to evaluate effectiveness be undertaken.

Examples of programs currently available in New Zealand are included in Appendix 1, page 53.

5. Medical Specialists. General practitioners and gynaecologists remain central to the management of pelvic pain. However, the co-existence of multiple causes of pelvic pain is recognised and involvement of other medical specialists and allied health professionals where appropriate is complementary to care and encouraged. We recommend that:

- 5.1. **Collaboration between the Medical Colleges** be encouraged, with consideration of training initiatives and facilitation of the development of a professional pathway in this area.
- 5.2. **A career pathway and training in Pelvic Pain for gynaecologists be considered**
- 5.3. **Improved remuneration via Medicare rebate** for the management of pelvic pain be made available to reflect the complex nature of presenting symptoms and prolonged consultations involved.
- 5.4. **That Government work with the Medical Colleges** to facilitate an adequately resourced multi health professional approach, working with all disciplines - gynaecology, gastroenterology, pain speciality, urology, paediatrics, physiotherapy, dietetics, occupational therapy, psychology etc, with adequate resources and revised referral processes.
- 5.5. **That GPs and paediatricians** who are 'first responders' in most cases of women who present with pelvic pain, are equipped with the necessary diagnostic tools, seamless

referrals, and easy access to a wide range of support services, so that women and girls can partner in their own health care, review their options and reach a collaborative treatment plan with a patient-centred approach. This recommendation is aligned but not limited to the following DOHA policies:

- a. *The Rural Women's General Practice Services (RWGPS) program*
- b. *Lifescrpts*
- c. *Medical Specialist Outreach Assistance Program (MSOAP)*
- d. *USOAP*

6. Patient-Centred Care To facilitate and simplify health care service delivery, we recommend:

- 6.1. **Access to first point of care** be improved with more appropriate and effective use of primary health care services
- 6.2. **That opportunities for health care provision through telemedicine** for girls and women in regional, rural and remote localities be expanded. Such a program provides easier access to specialists, without the time and expense involved in travelling to major centres.⁴³
- 6.3. **That gynaecological expertise** is incorporated into public hospital pain management units and that separate pelvic pain management units be created in public hospitals that provide significant women's health services.
- 6.4. **That where evidence of effectiveness can be demonstrated** for novel or established medical treatments for pelvic pain, that financial support for these medications or procedures be provided, to ensure equity of access.

7. Research. Australia has an impressive history of research in the area of endometriosis. We recommend that the NHMRC build on this record with:

- 7.1. **Epidemiological studies** on the prevalence of pelvic pain in Australia
- 7.2. **Research to quantify the impact of pelvic pain** on the health care system and individuals, with the outcome allowing for specific targeting of resources
- 7.3. **Collaborative approaches which link researchers across disciplines** to share the same data sets and knowledge to address causative factors and provide solution based improvements to the care and management of patients be encouraged

7.4. **Research into early intervention and prevention** strategies aimed specifically at adolescents

7.5. **A multidisciplinary approach to research** in all aspects of pelvic pain

Recommendations for research are included, but not limited to, those described in the reference paper by Rogers et al.³

8. Further Recommendations arising from research outcomes. That the dynamic nature of research outcomes in this area be recognised.

The Pelvic Pain Steering Committee recognises and endorses the comprehensive assessment of chronic pain illustrated in the *National Pain Strategy*, arising from the Pain Summit held in March 2010. This report begins the process of addressing these issues as they apply to pelvic pain, and as such is complementary to the *National Pain Strategy*. The Pelvic Pain Steering Committee is committed to supporting the roll-out of this report's recommendations, facilitating cooperation between the disciplines and improving the services currently available.

PART FOUR

CONCLUSION

The Pelvic Pain Report has highlighted the issues; presented the results from interviews with health professionals and patients (consumers); identified the barriers facing consumers, specialists, doctors, allied health practitioners and researchers; acknowledged existing associated strategies and policies, and provided solutions for integration into the health services.

In Part One the project sought answers to the following questions which are reflected in the project goals:

1. Is pelvic pain a serious health issue in Australia?
2. Are current services for women with pelvic pain easily accessible?
3. Can pelvic pain be managed in a more cost effective way?
4. How can current services for women with pelvic pain be enhanced?
5. In what way can medical treatment and management be improved?
6. Are health care providers sufficiently resourced to cope with women who have pelvic pain?
7. How can existing strategies be utilised more effectively?
8. What are the key research priorities?
9. Who takes responsibility?

There is no doubt that conditions causing pelvic pain are common in Australia and pose a National and Global cause of grave concern. Endometriosis alone affects at least 1 in 10 girls and women with significant personal, social and economic fallout, and the many additional causes for chronic pelvic pain add to the enormity of the problem. These conditions are often ignored and bear the social, personal and economic burden of years of diagnostic delay, variably effective treatments, long term personal suffering, and major economic consequences.

“Who takes responsibility?” is posed as Question 9 of the report (Part One, page 10) and is restated above. This project supports individuals taking personal responsibility for their health through education and recognised self-management strategies. It believes the answer lies in a partnership between patient, health service providers and funders. There are important roles and expectations of each.

For example, there is an expectation that the patient will present well informed, in a timely manner and be actively engaged in their health care. There is a requirement that the funder will deliver the best possible health care to achieve the best possible health outcomes. Without prejudice, this report has endeavoured to highlight deficiencies and provide workable solutions within that framework.

By its own admission, Government acknowledges that pain is a fiscal and economic drain. Women whose lives are severely compromised are frequent users of disability benefits and many women are falling short of reaching their full potential. At least 1 in 10 girls in Australia grows up with symptoms severely compromising their schooling, career path, social growth, and ability to be productive citizens. Conditions causing pelvic pain rob women of confidence, motivation and ambition.

Endometriosis and conditions causing pelvic pain cost billions; in health care costs, in absenteeism, in presenteeism, in lost productivity, and in social and scientific environs. Yet, despite the evidence and commonality, endometriosis and conditions causing pelvic pain remain poorly understood, poorly diagnosed, and poorly treated and managed. Using current conservative estimates, endometriosis alone costs Australians 6.6 Billion Dollars in direct costs. This does not include the indirect costs to women and their families. There is little question that investment in pelvic pain services will provide an unparalleled economic return to individuals, families, communities and the economy through completed education, paid employment, and improved quality of life.

Regardless of the precise costs of endometriosis (and conditions causing pelvic pain) to society, there seems little doubt that research into this disease is significantly under-funded relative to other diseases with major health care burdens. The reason for this underfunding is unclear, but may reflect to some extent the practical difficulties of developing competitive research proposals when working on such a complex and poorly understood disease, which only affects women.³

Advisors to the project indicate our health system isn't working as well as it could and pelvic pain services are fragmented and limited. Many of the problems identified in Part Two remain unchanged from the research conducted in New Zealand in 1990 and 1996, and current literature and research confirm they remain unsolved issues.^{15,18} Even more sadly, women's health stories recorded years ago follow a similar thread as those heard today. The case histories documented in Appendix II, page 58 revealed a staggering diagnostic delay to diagnosis from first presentation of symptoms.

There is widespread patient dissatisfaction with the inequities in accessing and receiving treatment, which is dependent on locality and specialist resource. There are a myriad of reasons for these discrepancies, but all can be addressed through a thoughtful, multidisciplinary, patient-centered approach.

Early intervention could be more effectively and appropriately managed at primary health level. GP and paediatrician awareness and education of the prevalence, presenting symptoms, primary care management and referral processes require major attention.

To affect an overall and improved shift in outcomes for women and girls with conditions causing pelvic pain the focus has to be multi-disciplinary. As eloquently explained by Professor Peter Rogers: *"No single group owns the expertise that will allow them to make progress in this area".*

It is encouraging that the Australian Government acknowledges the enormous personal, social, and economic cost of chronic pain to the community and is taking action by adopting policies to address immediate and future health challenges. It is reassuring that Government is focused on health promotion and prevention and the importance of addressing the barriers faced by many disadvantaged women and girls. Government states it is committed to *“maintaining and developing health services and prevention programs to treat and avoid disease through targeting health issues that will have the greatest impact over the next two decades.”* Government sees the benefits of actions being drawn from *“existing responses”* and taking a proactive stance on prevention of chronic disease through controlling risk factors.

The recommendations in this report integrate with those of the National Pain Strategy. They are also suitable for integration into the following existing DOHA health strategies and policies:

- Women’s Health
- Diseases and Conditions
- Chronic Conditions
- Young People in Australia
- Indigenous Australians
- Rural and Remote

Accepting conditions causing pelvic pain as a major health issue is the first step to limiting the cost, streamlining the patient journey, and realising positive outcomes. Unless this is accepted as a public health issue, endeavours to make an impact on improving the treatment of conditions causing pelvic pain and the outcomes for our patients will be stalled. With the recent statement that health reform initiatives are *“well and truly on track”*, it would be inconceivable not to recognise and acknowledge the health and welfare of Australian women and girls during the prime of their lives.

This report begins the process of a whole of community approach to improving the quality of life of Australian women and girls and their families. Issues highlighted in this document are of particular importance to all women who, according to the last census, represent more than 50% of the voting population in Australia.

The barriers to providing improved patient services are not insurmountable and solutions for immediate introduction have been recommended.

The question remaining to be asked is whether Australian Society is prepared to leave this large population group behind?

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ANZCA	Australia New Zealand College of Anaesthetists. http://www.anzca.org
APS	Australian Pain Society http://www.apsoc.org.au
ASPOG	Australian Society for Psychosocial Obstetrics and Gynaecology
ASRM	American Society for Reproductive Medicine
ATHS	Australasian TeleHealth Society
CBT	Cognitive Behavioural Therapy
COAG	Council of Australian Governments
CPP	Chronic Pelvic Pain
DALY	Disability Adjusted Life Year
DOHA	Department of Health and Ageing http://www.health.gov.au
ECCA	Endometriosis Care Centre of Australia http://www.ecca.com.au
ENZ	Endometriosis New Zealand http://www.nzendo.co.nz
ESHRE	European Society for Human Reproduction and Embryology
ESIG	Endometriosis Special Interest Group http://www.nzendo.co.nz/endometriosis-special-interest-group.html
FPM	Faculty of Pain Medicine. http://www.anzca.edu.au/news/announcements/faculty-of-pain-medicine-2011
GP	General Practitioner
GSWH	Global Study of Women's Health
IASP	International Association for Study of Pain http://www.iasp-pain.org
IBD	Inflammatory Bowel Disease
IBS	Irritable Bowel Syndrome
ICDP	Indigenous Chronic Disease Package
IPPS	International Pelvic Pain Society http://www.pelvicpain.org
ISGE	International Society for Gynaecologic Endoscopy
me	Menstrual Health and Endometriosis educational program in schools. www.me.school.nz
MSOAP	Medical Specialist Outreach Assistance Program
NGO	Non-Government Organisation
NIH	National Institute of Health
NHPAC	Australian National Chronic Disease Strategy
NSAID	Non-Steroidal Anti Inflammatory
NZ	New Zealand
O&G	Obstetrics and Gynaecology
PID	Pelvic Inflammatory Disease
PPP	Patient Partnering Program for District Health Boards (Public Hospitals) in NZ http://www.nzendo.co.nz/patient-partnering-programme.html
PPP	Persistent Pelvic Pain

QENDO	Endometriosis Association (Queensland) Inc. http://www.qendo.org.au
RACGP	College of General Practitioners http://www.racgp.org.au
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists http://www.ranzcog.edu.au/
RCOG	Royal College of Obstetricians and Gynaecologists
RWGPS	Rural Women's General Practice Service
Shine	Sexual Health Information Networking and Education SA
STI	Sexually Transmitted Infection
UK	United Kingdom
UNSW	University of New South Wales
USA	United States of America
UTHSCSA	University of Texas Health Science Centre in San Antonio
YES	Young Endometriosis Supporters – a subgroup of Endometriosis NZ http://www.facebook.com/facebook?ref=pf/r.php?locale=en_US#!/pages/YES-Young-Endometriosis-Supporters/44787758532
WERF	World Endometriosis Research Foundation
WES	World Endometriosis Society
WHO	World Health Organisation

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- Australian Pain Management Association
- Australian Pain Society
- Australasian Gynaecological Endoscopy and Surgery society
- Australia New Zealand College of Anaesthetists
- Chronic Pain Australia
- Department of Health and Ageing Policies and strategies
- Endometriosis New Zealand
- European Society Health and Reproductive Endocrinology
- Faculty of Pain Medicine
- International Association for the Study of Pain
- International Pelvic Pain Society
- National Association of Specialist Obstetricians and Gynaecologists
- Painaustralia and the National Pain Strategy
- Royal Australian and New Zealand College of Obstetricians and Gynaecologists
- Royal Australian College of General Practitioners
- World Endometriosis Society
- World Endometriosis Research Foundation

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APPENDICES

APPENDIX I

SERVICES AVAILABLE IN NEW ZEALAND

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Endometriosis New Zealand-a national organisation pivotal to facilitating the wellness of women.

Bush D. In Rombauts L, ed. World Endometriosis Society:ejournal 2009;11(2):6-9. <http://www.endometriosis.ca/WES-e-Journal-April-2009.pdf>

Background

The leap in international awareness of endometriosis in the early 1980s, impacted on changing the face of endometriosis throughout the world. These largely patient-led campaigns came from UK, USA, Australia and New Zealand. Functioning independently, these groups began a groundswell of action to improve awareness and treatment for women and girls with endometriosis.

This article focuses on Endometriosis New Zealand (ENZ) (www.nzendo.co.nz).

Beginning in 1985 Endometriosis New Zealand became a Registered Charitable Trust in January 1994, known as the New Zealand Endometriosis Foundation Incorporated (NZEI). Now known as Endometriosis New Zealand (ENZ), the organisation seeks to provide pragmatic solutions to the burdens that endometriosis creates. The foundations laid in the mid 1980s, focusing on education; information and support, remain core to ENZ services today.

Additionally the group has initiated specialised programs, fostered research and actively lobbied for better outcomes for the combined market involved with endometriosis, including the New Zealand Government.

Early research outcomes pave the way for future planning

The founders became acutely aware of women's stories repetitively claiming frustrations and concerns about delayed diagnosis, lack of being understood, poor treatment options, compromised quality of life and despair about fertility. What seemed most obvious to women with endometriosis was that, had they been taken seriously when presenting with symptoms in the teen years, their adult lives could have been different. Avenues to confirm well-founded suspicions about such issues were explored through member surveys (unpublished observations) and commissioned investigation. (Grace, 1994; McGuiness *et al*, 1990).

Some of the strategies, services and programs implemented by ENZ, were based on what we termed 'action research' (that which is known to be needed but not qualified in published data). The

information gleaned and past ENZ archived documentation adds weight to the now familiar international data acknowledged in other studies (APPG UK, 2005; Ballard *et al*, 2006).

Why multi-disciplinary holistic approach through Centres of Excellence?

Endometriosis can be physically and emotionally painful. Years of experiencing significant symptoms often interfering with quality of life and fertility and economic losses caused by disruption of study, occupational income and damaged social relationships, make it understandable that a woman can develop changed cognitive behavioural patterns. Often surgical or medical treatment on its own, will not address her total wellbeing. Gynaecologists specialising in endometriosis in New Zealand accept ENZ programs which has been achieved through respectful, longstanding professional association underpinned by the aligned goal to improve health outcomes for women and girls with endometriosis.

Several Centres of Excellence (CoE) offering all available treatments in a multi-disciplinary holistic context, are available in New Zealand (Bush and East, 2009).

SPECIALISED PROGRAMS AND SERVICES

Education

A fervently held belief within ENZ is that education is key to changing what is viewed as unacceptable data. Clinicians require education to heighten their index of suspicion and lower their threshold to offer diagnostic laparoscopy. Patients require education to recognise symptoms, acknowledge departures from normal health and develop the confidence to request referral for gynaecological consultation. It seems logical that education can change the course of history for endometriosis.

ENZ has provided a multi-pronged approach to education spanning more than 20 years outreaching general practitioners, family planning associations, public health organisations, public and private hospital staff, student health services, Maori and Pacific women and ENZ Support Groups.

Adolescent education

The last 10 years has seen a concentration of adolescent education in schools with the **me** (**m**enstrual health and **e**ndometriosis) programme. ENZ lays high priority on education for young women. ENZ surveyed its members in the 1980s and 1990s and found that:

- Symptom onset was often experienced from the outset of menses or during the teen years
- Common symptoms experienced in adolescence included
 - period pain significant enough to warrant absenteeism
 - bowel associated problems (eg. diarrhoea with period, bloating, pain on defecation)
 - lower back pain
 - tiredness
 - dyspareunia

- The pill was the most common first line treatment offered to teenagers presenting with suggestive symptoms. Most were not advised their symptoms could be related to endometriosis.
- Despite earlier presentation of symptoms, diagnosis was often significantly delayed into a woman's 30s or 40s, or until after fertility problems presented.

As a result of these findings and a growing realisation of the magnitude of the problem in young women, Ms Deborah Bush, QSM, designed **me**, a curriculum-approved program operating through ENZ.

me

me was developed to raise awareness of endometriosis in young women addressing diagnostic delay to improve quality of life and avoid potentially compromised fertility downstream. After trial in the mid 1990s and subject to rigorous continual evaluation, it is unique, fun, highly accepted, age-appropriate, and professional, with schools having an expectation it will be available for their students annually. **me** comes complete with resources and website and has had international exposure (www.me.school.nz). Results from **me** confirm it allows for early management of symptoms, diagnosis and improved quality of life. Further research is needed to assess whether future fertility is improved. Outcomes monitored in one Centre of Excellence since 2001 show a three-fold increase in young women under 20 presenting with symptoms suggestive of endometriosis. Of those proceeding to laparoscopy 96% were diagnosed with endometriosis. This confirms that a suspicion of endometriosis from diligent clinical history taking, allows accurate prediction of the disease prior to laparoscopy (Bush and East, 2009).

These results also suggest that a clinical suspicion can lead to appropriate medical intervention as a first line treatment option in this age group, as it is not always appropriate to proceed to laparoscopy in the first instance.

Patient Partnering Program (PPP)

In 1997, the author designed a patient-based educational and counselling curriculum to integrate into the Centre of Excellence at Oxford Clinic Women's Health, Endometriosis Treatment Centre in Christchurch (Bush and East, 2009). This laid the foundation for the ENZ Patient Partnering Program in New Zealand hospitals. PPP supports the multi-disciplinary holistic approach to best practice treatment (D'Hooghe and Hummelshoj, 2006). Piloted at Christchurch Women's Hospital in 2004, the program now functions successfully at other District Health Board's (DHB's or hospitals) in New Zealand, filling treatment gaps by providing patients with broader management and lifestyle strategies, and education and resource support to hospital staff. This is a cost effective beneficial situation for patients, staff and doctors treating endometriosis to improve the patient journey and outcomes.

With sound understanding, information and support women generally feel in control of their condition, have increased personal productivity, fewer overall health costs and increased comfort as a result of comprehensive monitoring and holistic care. PPP has been analysed assessing performance, accountability and value-added health care, supported by independent research (K.Renner and C.V. Stephens, personal communication, 2009).

Workforce Issue Solutions for Endometriosis (WISE)

Endometriosis is a workforce issue costing countries millions every single year in lost work days (Simoens *et al*, 2007). It is essential to manage and mobilise the endometriosis workforce by giving staff and management strategies to cope more productively, and access help and treatment for endometriosis. WISE provides workforce solutions to staff, employers and endometriosis sickness beneficiaries.

Advocacy

In 2008 ENZ secured a contract with the New Zealand government to investigate the need for endometriosis treatment guidelines or pathways. The ENZ Trust Board established and facilitates an Endometriosis Special Interest Group (ESIG). ENZ is collaborating with government to have the first phase of recommendations introduced. (ENZ Report 2009).

Cultural awareness and programs

New Zealand is a bi-cultural country with a multi-cultural population. ENZ continues to be aware of the need to develop outreach programs for different cultural communities. Presentations have been made to Maori health workers at hui (meetings) and collaborative efforts across other health sectors are being enhanced to ensure improved and accurate awareness. As part of the 2009 International Endometriosis Awareness week, ENZ released the Maori name for endometriosis. The word, mate kirikōpū, has been described as a taonga (gift) to our people. ENZ has recently appointed two new Board members to grow awareness and improve the health journey for Maori girls and women and women from other cultures.

Quality assurance

Endometriosis New Zealand is committed to quality assurance. The goal has always been to exceed expectation through measurable and accountable processes, governed by a dedicated Trust Board which has a broad range of expertise. Peer review processes, service user evaluative measures, independent review and professional delivery across all services and programs, appropriate for the time and conditions, are seen as a fundamental requirement and core to our organisation thereby giving confidence to all our stakeholders.

Conclusion

Tens of thousands of women and girls throughout New Zealand and abroad have contacted ENZ over the years – many desperate for information and support. The passion and drive to change the course

of history of endometriosis has relied on the unique skills and talents from within the organisation setting global standards of excellence in developing and delivering initiatives, providing services, fostering research and actively lobbying. Working within financial constraints, ENZ has been a major player in contributing to facilitate the wellness of women and girls with endometriosis.

ENZ aims to continue building on the work achieved and develop more opportunities to foster research and align with others in its target population for improved outcomes.

Intrinsic to success has been the respect, collaboration and cooperation spanning more than two decades from gynaecologists, RANZCOG and other associates and stakeholders who have embraced ENZ's philosophy and programs . Once Endometriosis Organisations in the world are able to forge this connection, the possibilities for addressing the notorious issues are endless.

ENZ has been a recipient of the following awards:

- Commonwealth Award for Excellence in Women's Health
- Paul Newman Own Foundation Award
- NZ Health Innovation Award 2007 for *me*

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APPENDIX II

CASE STUDIES

These patient history vignettes review the experiences expressed by the women interviewed for the case studies. They explain how their experiences of physical, sexual, emotional or mental health have affected them through having one or more of the pelvic pain conditions.

Some women have created uniquely personal and collective strategies for self-care and coping with their conditions, relationships, schooling and career and often mental illness.

Some patient participants were willing to speak publicly to highlight their plight.

The general sense is that many of the women felt a lack of control at a young age when symptoms were normalised. They spoke of emotional distancing and distrust in family and health professionals. The women relay their frustrations about accessing care, about being believed, about experiences with stigma (both internalised and externalised) associated with having a condition or conditions causing debilitating pelvic pain.

Comments from these women and others are recorded in 'issues and barriers to accessing care' in Part Two. Tragically, one woman was not here to retell her story and her parents were keen for her story to be used to help others.

Social network comments (2011) from women in New Zealand and Australia follow these case studies and highlight further the burdens faced by women and girls with conditions causing pelvic pain.

PATIENT HISTORY VIGNETTES

PATIENT ONE

Miss K. New South Wales. Age 23 years

Symptom onset 10 years. Time to diagnosis of cause of pain: 11 years

More than 100 medical consultations including interstate – 5 gynaecologists and 15 general practitioners to make the diagnosis of endometriosis. Lack of willingness to refer. Pain relief not paid for by healthcare card. Profound secondary psychosocial consequences.

PATIENT TWO

Miss M. New Zealand. Age 32 years

Symptom onset 13 years. Time to diagnosis of cause of pain: 10 years

16 laparoscopies; referred appropriately to tertiary specialists along her treatment pathway; died post operatively after the 16th laparoscopic procedure

PATIENT THREE

Miss C. South Australia. 29 years

Symptom onset 12 years. Time to diagnosis of cause of pain: 24 years

Consulted numerous GP's, 2x Orthopaedic Surgeons, 4x subspecialist physicians, 2 multi-disciplinary pain units, 3x naturopaths, multiple alternative and complementary medicine practitioners. Medication costs per month: \$300.00. Disbelieved frequently. Ultimately pursued her own multi-disciplinary approach to treatment with positive results.

PATIENT FOUR

Miss S. South Australia. 28 years

Symptom onset age 11 years. Time to diagnosis of cause of pain: 8 years.

Yet to be able to work, on Disability Support Pension. Advice from health services has included "It's in your head", "Have a baby, it will clear up", "You can't get endometriosis if you haven't been sexually active", "It's only periods, get over it", "You're in the too hard basket," "You need to tell your stomach to stop hurting, and it will stop". Suffers from depression and anxiety.

PATIENT FIVE

Ms A. Queensland. 34 years

Symptom onset 11 years. Time to diagnosis of cause of pain: 7 years

Heavy reliance on analgesics, 7 laparoscopies, hysterectomy, bilateral oophorectomy, bowel resection with ileostomy. Sought the 'best' endometriosis specialists. Remortgaged house to cover GAP expenses. Career declined through absenteeism and 'unreliability'. Told pain was normal.

PATIENT SIX

Mrs L. New Zealand. 47 years.

Symptom onset teen years. Time to diagnosis of cause of pain: 20 years

Unable to sit without pain. Incapacitated. Had to resign from executive position. Had endometriosis diagnosed and treated in 2010 with laparoscopy and then hysterectomy. Pain persisted. Felt treatment options limited in NZ. Sought help in Sydney. Xray-guided block of pudendal nerve, due for pudendal nerve release later this year.

PATIENT SEVEN

Mrs E. NSW. 49 years.

Symptom onset 19 years. Time to diagnosis of cause of pain: 20 years

Multiple laparoscopies, hysterectomy for prolapse, and revision of prolapse repair. Pelvic myalgia post-surgery. Physiotherapy, antidepressants, pudendal nerve block.

PATIENT EIGHT

Mrs R. New South Wales. 55 years.

Symptom onset: teen years. Time to diagnosis of cause of pain: 20+ years

Multiple laparoscopies for endometriosis, hysterectomy at 36 years. ? pudendal nerve entrapment – pudendal nerve blocks and Botox to pelvic floor muscles. Some improvement, treatment ongoing.

SOCIAL NETWORK COMMENTS March – July 2011

Skye wrote: “Your story sounds so much like mine, so bloody horrible. I was diagnosed with Pelvic Inflammatory Disease and irritable bowels before I had my surgery in August. My ovary was stuck in my tummy wall - 4.5 hours in surgery. It’s amazing that we get through this. You think your life is going to be magical from then on too... I am on the pill. I think that is what is making this worse.”

Victoria wrote: “I was exactly like that until they put me on a new pill... took periods completely away and was fantastic... can't quite remember what it is called right now though.”

Emma wrote: “Hey, I'm a 19 year old student. Had my endo op just over a year ago, hasn't been smooth sailing since then. They have looked inside my bladder and am now going to look inside my bowel, soo over all of the specialists, wish I could just have a normal day. ☹️”

Courtney wrote: “Hey, I'm 18, have endo, had 2 surgeries, Mirena etc. Pain is worse and I've been getting new symptoms also...”

Tracey wrote: “Anyone had a Mirena after Endo surgery? I had my 2nd surgery nearly 2 yrs ago and a Mirena inserted. I had been fine since (even no periods) up until a few months ago when I started to get mild pain and then this month a period and a night of bad pain with the "works" attached... I remember the pain, it is endo but I feel very gutted because I was sure the Mirena was supposed to help!”

Sophie wrote: “I had surgery for Endometriosis in January. They found stage two Endometriosis. My tummy has been getting swollen to the point where I look nine months pregnant! Has anyone else been worse after having this surgery? My period pain is even worse.”

Carol wrote: “Male specialist was also very rough causing a lot of pain and made me feel so small. I had a male specialist who told me it was in my head. I was also told by 2 different Dr's on different visits that I had PID when I have never had a STI in my life! I've been with my partner for more than 6 years.”

Nessa wrote: “My pain never completely went away after my laparoscopy. It's starting to get a bit worse now. My periods were never painful & only lasted 3 days, but the pain in between was fetal position on the couch & wanting to puke.”

Sally wrote: “After my laparoscopy I didn't notice any changes but I also got endo back straight away, and it was the pain that was a put off. I'm lucky if I have 1 pain free week out of 4.”

Toni wrote: “I had my 2nd lap surgery on Friday with a Specialist Endo Surgeon. I'd had chronic left,

right side pelvic pain, bladder pains like UTI symptoms, constant aching sore lower back, legs. My back pain has gone it's fantastic to not feel the pain which I've had for months. They inserted a Mirena, so hoping now the endo has been removed properly this time. If symptoms and/or pains return I will have to seriously consider a hysterectomy which I don't want but am now out of options!"

Jessica wrote: "I had my 2nd lap last June. Since then I have had a sharp stabbing pain in my left pelvic area and a burning sensation in my bladder. I saw my specialist yesterday to hear devastating news and I need MORE surgery. I'm tired. I'm in pain all the time. I'm scared. I just wonder what will become of me as no one can give me answers or guarantees."

Anastasia wrote: "I have been going through hell with that time of the month for 8 years now and all my GP said was to suck it up and kept putting me onto different pills. I finally gave up and went to see a gynae and he listened to what I had to say. He then said he was 90% sure I had endometriosis. I had severe endometriosis removed. I was so upset when I found out how common this is and how many GP's won't even think about the possibility. I want to thank your group for all the work you have been doing and for the support you are giving people like me who had no idea what was going on. I feel this sort of issue should be thought about and 'advertised' more. Thank you Endometriosis New Zealand for helping me get through this tough time."

Jam wrote: "I was diagnosed with endo in Feb, I've tried being gluten free also which didn't help before I was diagnosed. I also have been a veggie for 22years and don't eat seafood & can no longer have dairy apart from cheese... so I don't think veggies is the cause of the pain, or making it worse. Pain's always there like a headache that turns into a migraine every so often. I bought Flaxseed omega-3 tablets as well as a multi vitamin and my GP prescribed Ponstan along with codeine to use on the days where I can't do anything but curl in a ball and try not to think about how much I want to claw my side."

Jayne wrote: "Anyone know any pain relief that works? I've tried Ibuprofen, Panadol, Voltaren and had a disastrous experience with tramadol and combinations of them. Seeing GP tomorrow, but I don't really see any light at the end of the pain tunnel."

Sarah wrote: "Hey, could someone tell me when I should expect to start feeling better after my surgery of discovering and removing severe endometriosis? Is it usual to be feeling tired, sore and unwell still? If so, how long will this last? Thanks!"

Elizabeth wrote: "I know who my true friends are that have been there for me throughout my 3 surgeries, pregnancy and after my baby. Yesterday I also found out I'm infertile and I'm not even 21 yet! My Mum, Gran and ex-partner have all been so supportive and helped by getting awareness out there too. To the people who don't support us women with the cruel condition, well we don't need them adding extra stress in our lives."

Lisa wrote: "I was only with my partner for a few months when I first got diagnosed - and what a support he still is today. I had to give up work when my symptoms got so bad, then the Christchurch earthquakes! When I had both my surgeries, he took the whole day off and waited for me! When I stayed over-night, he slept in the lazy boy! It takes a lot of understanding and patience to be with someone with Endometriosis and I couldn't ask for anyone better! It's safe to say I have a gem."

Neon wrote: "I went to my doctor today about serious on going period pain. 2 weeks ago (right in the middle of Uni exams) it's been pretty much the worst it's ever been. She said I might have Endo, and I've got to see a specialist and might have to have surgery. But she asked me about bowel problems. I was hospitalised with a stomach ache so bad they had to administer Morphine a couple of years ago. I've suffered stomach pains and digestion issues my entire life though, so I never thought that it could be a problem related to my period before. But it might make a lot of sense now, since over the past couple of years I've started to have difficulty figuring out whether I'm experiencing pain because of my period or because of bowel issues. And now I'm also wondering about whether my 'stress related' tummy pains that used to wake me up in the night during times that I had high anxiety might be linked to this as well, even though a Doctor at the time thought it was completely psychosomatic..."

Ann-Marie wrote: "I got told I had this last January when I had my operation. I thought that was the end of the hell but no, it had to come back and this time ten times worse. Tablets not giving me any pain relief and now I'm on morphine. It's a living night-mare. Hopefully one day they will find a cure for it and we will be pain free from this horrible illness."

Westerly wrote: "Oh, and depression, how these diseases affect your mentality and how to live 'moment to moment'...with suggestions for pain from those who have acute pain...such as suggested tens machine providers, aromatherapy, massage, and local health and well-being providers that are AWARE of Endometriosis and Adenomyosis ...thanks for your time."

APPENDIX III

GUIDELINES FOR THE TREATMENT OF ENDOMETRIOSIS

1. **European Society for Human Reproduction and Embryology (ESHRE)**

Guideline for the diagnosis and treatment of endometriosis

Human Reproduction Vol.20,no.10 pp.2698-2704,2005 ⁹

www.humrep.oxfordjournals.org/cgi/content/abstract/dei135v1

- a widely used guideline across Europe and the UK, useful in tabling clinical evidence, symptoms, aspects of surgical and medical treatments and the importance of the role of patient lead services.

2. **Royal College of Obstetricians and Gynaecologists (RCOG)**

Green-top Guideline no.24, October 2006

The investigation and management of endometriosis

www.rcog.org.uk/index.asp?PageID=517

- The second edition of this guideline 'provides clinicians with up to date information about the diagnosis and treatment of endometriosis, based upon the best available evidence. The treatment options are examined in the light of presenting symptoms and associated infertility'
- The guideline recommends a multi-disciplinary approach involving a pain clinic and counselling. A 'Gold Standard' diagnostic test is defined. Of particular importance, the management of severe or deeply infiltrating endometriosis is described as being complex with referral to a centre with necessary expertise to offer all available treatments in a multi-disciplinary context recommended. The guideline is useful in posing questions and offers evidence based responses.

3. **American Society for Reproductive Medicine (ASRM) - First Guideline**

Treatment of Pelvic Pain Associated with Endometriosis

Fertil Steril 2006;86(suppl 4):S18-27. 2006

[www.fertstert.org/article/S0015-0282\(06\)03410-8/fulltext](http://www.fertstert.org/article/S0015-0282(06)03410-8/fulltext)

- Produced by the Practice Committee of the American Society for Reproductive Medicine in Alabama. The paper is useful in identifying endometriosis as the most common gynaecological disorder being found in 70% of patients with chronic pelvic pain, in the differential diagnosis of pelvic pain and mechanisms of pain. Key points from the summary and conclusion have application to Australia and NZ.

4. **American Society for Reproductive Medicine (ASRM) - Second Guideline**

Treatment of Endometriosis and Infertility

Fertil Steril 2006;86(suppl 4):S156-60. 2006

www.asrm.org/

- Produced by the Practice Committee of the American Society for Reproductive Medicine in Alabama. The paper demonstrates an association between endometriosis and infertility, and the biologic mechanisms that may link endometriosis to infertility. Associated diagnosis and staging is explained and efficacy of medical and surgical management in this demographic is supported with research. The clinical approach to infertile women with endometriosis could be considered appropriate to Australia and NZ, as are aspects from the summary and recommendations.

5. **Danish National institute of Health**

Danish National Guidelines

Guidelines for specialist treatment, February 2002

www.endometriosiszone.org/display.asp?page=pr_danish-endo-guidelines

- Relies on correct staging of disease to refer women with moderate to severe endometriosis (stage 111 & 1V) to centres of excellence for treatment. Two such centres are noted and patient treatment for all related expenses is covered by Government. This protocol could have application to NZ.

6. **Study appraising existing international guidelines for the management of pelvic pain.**

BJOG An International Journal of Obstetrics and Gynaecology 2006; 113:749-757.

Guidelines for the management of pelvic pain associated with endometriosis: a systematic appraisal of their quality.

www.ncbi.nlm.nih.gov/pubmed/16827756

- This study appraising the existing international guidelines revealed that *'guidelines for the management of pelvic pain associated with endometriosis do not comply with the recommendations for high quality standards'*. This study states that *'guidelines can improve the quality, appropriateness and cost-effectiveness of health care in endometriosis'*.

SUMMARY OF GUIDELINES

Some aspects of the existing guidelines (ESHRE, ASRM, and Royal College of O & G Green Top Guideline number 24) were noted as having some relevance to the treatment of endometriosis and conditions causing pelvic pain in Australia and New Zealand and remain useful as a beginning point for the development of Australian guidelines. However, our search did not identify any guidelines reflecting the Australian situation and resources. Guidelines are evolutionary and need to be tailor made.

While the study appraising the quality of the existing guidelines favoured guidelines for improving treatment, management and cost effectiveness, using validated and reliable appraisal tools, it revealed an overall non-compliance in meeting high quality standards.

APPENDIX IV

Figure 1. Monetary loss from endometriosis-associated work absenteeism and presenteeism.
 Ref: Nnoaham. Endometriosis, quality of life and work. Fertil Steril 2011.

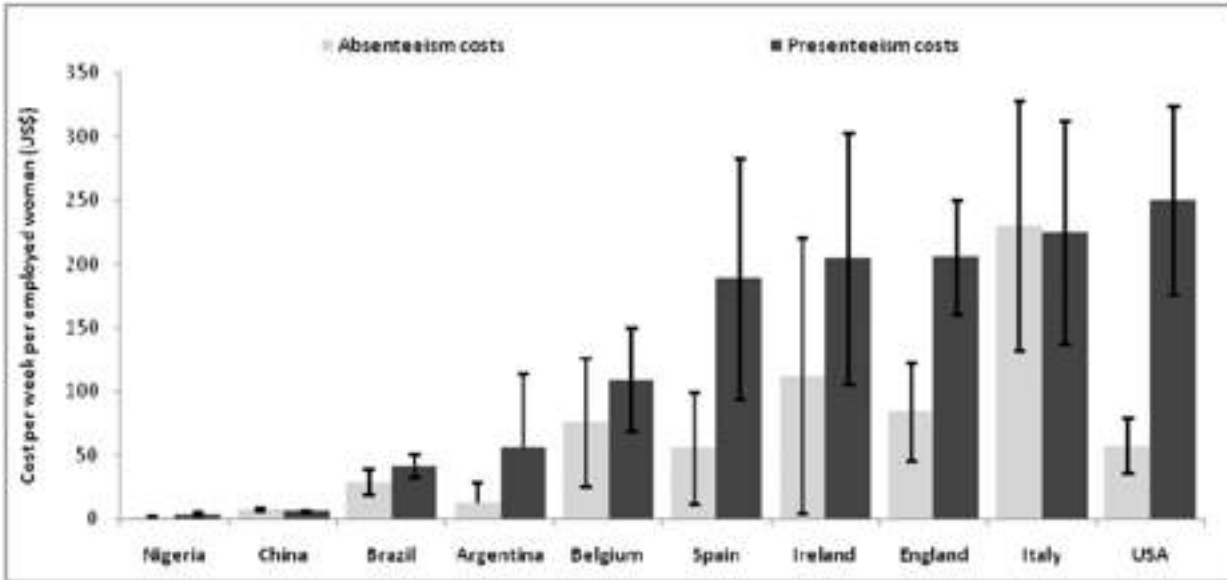
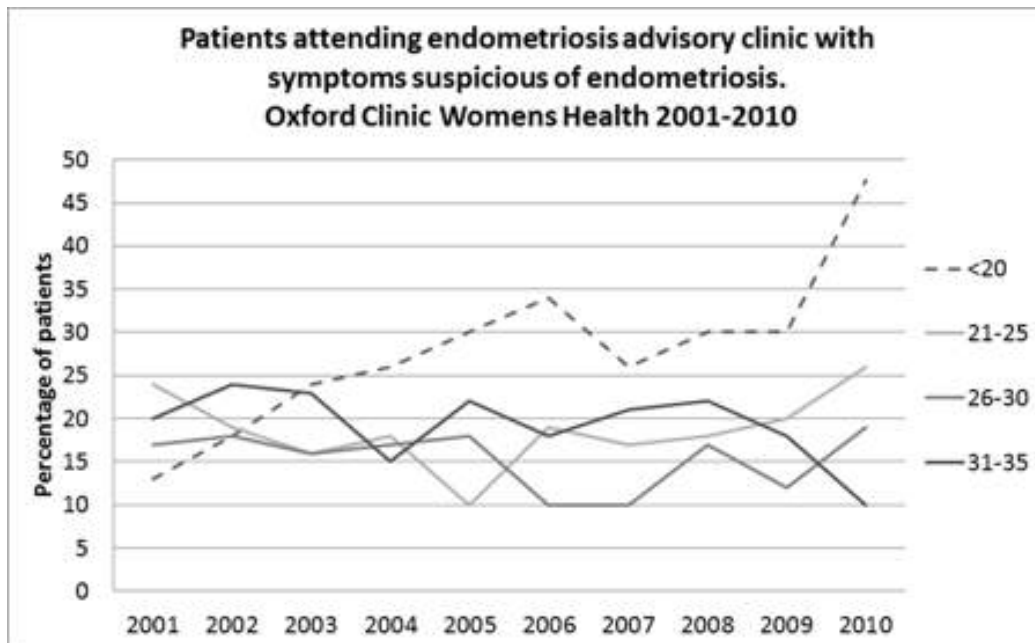


Figure 2. Graph to show increased trend of patients under 20 years of age, presenting with symptoms suspicious of endometriosis at the Oxford Clinic Women’s Health in Christchurch New Zealand, where the ‘me’ educational program has been operational in secondary schools since 1997. Key presenting symptoms include: primary dysmenorrhoea, lower back pain, bowel symptoms e.g. bloating, pain on defecation and fatigue. Outcome of surgery: 94% underwent laparoscopic review and of those 96% were diagnosed with endometriosis; 49% with mild (stage 1) disease.



APPENDIX V PELVIC PAIN STEERING COMMITTEE

Deborah Bush QSM, Dip Tchg, LSB **Chief Executive, Endometriosis New Zealand**

Deborah Bush co-founded Endometriosis New Zealand (ENZ) and is currently based in Christchurch, New Zealand. She has had a global influence on health promotion and prevention of endometriosis and is recognised as having expert knowledge of the personal, societal and financial burden endometriosis imposes. She sits on the International Endometriosis Zone Advisory Board. More recently she has developed an interest in the broader aspects of pelvic pain.

Deborah has over 25 years of health industry experience and has established and maintains:

- a national charitable non-government organisation which represents girls and women with endometriosis, works with those who treat the condition, and fosters research
- preventive health initiatives and innovative programs for schools, the workplace and hospitals
- a private life coaching business for women and girls who have endometriosis and pelvic pain

To enable the development of ENZ, she has successfully forged professional relationships with businesses, allied health organisations, sponsors and funders, health professionals, schools, and women and girls and was contracted to report to the New Zealand Government in 2009. Using her experience as a qualified senior middle and secondary school teacher, Deborah developed the world's first Menstrual Health and Endometriosis adolescent education program for schools in 1997. Known as 'me', it was a New Zealand Health Innovation Award Finalist. In 1999 she developed and implemented a comprehensive, patient centred program, known as EPP (Endometriosis and Pelvic Pain) Coaching and Consultancy. Operating at clinics offering multi-disciplinary expertise, it formed the basis of the Patient Partnering Program offered by Endometriosis NZ to public hospitals (including inter-disciplinary education to health teams.) Recognising endometriosis and pelvic pain as a major workforce issue, she developed a Workplace Wellness Program in 2010.

Deborah's professional background in stage performance and media training have been useful in representing the cause and the issues regularly to a wide range of media outlets. She is a popular after dinner speaker, and has frequently presented at academic conferences in New Zealand, Australia, Malaysia, India, Europe, the UK and USA.

Deborah's contribution has been reflected in the following national and international awards:

- Queens Service Medal (QSM), Queen's Birthday Honours, 2003.
- Paul Newman Award for Services to Women's Health, 2007.
- 'International Outstanding Service Award' commemorating the 100th Year Celebration of International Women's Day, 2011.
- 'Commonwealth Award for Excellence in Women's Health' to ENZ under her leadership
- 'Woman of the Biennium Award' 2012 – 2014. Awarded by Zonta International (D16)

Contact Deborah: deborah@nzendo.org.nz

Dr Susan Evans MBBS FRANZCOG GAICD FFPMANZCA

Gynaecologist, Laparoscopic Surgeon, Specialist Pain Medicine Physician

Dr Susan Evans is a gynaecologist in Adelaide, Australia specialising in the management of pelvic pain. She has a long held interest in improving the care of women and girls through improved public awareness, clinical practice, education, and multidisciplinary care.

Current Positions:

- Gynaecologist and Laparoscopic Surgeon 1996 – Current
- Specialist Pain Medicine Physician 2010 - Current
- Honorary Clinical Lecturer, University of Adelaide 2009 – Current
- Visiting gynaecologist, Women’s and Children’s Hospital, Adelaide 1996 – Current
- Member of Endometriosis Special Interest Group – New Zealand (ESIG) 2010 – Current

Susan completed her medical degree at the University of Tasmania in 1984, receiving the Surgery Prize in her final year, the Schering Prize for Original Research (1988 and 1992), and the Australian Gynaecological Endoscopy Society Travelling Fellowship in 1995. Her book ‘Endometriosis and Pelvic Pain’ is internationally recommended for both women and girls with pain, and the professionals who care for them. Her pelvic pain e-book for girls, women, their partners and families was released for free distribution in September 2011. Susan has contributed to the education of doctors and the public via:

- Her contribution to the *‘Integrative Medical Textbook’* edited by Dr Kerry Phelp outlining a contemporary integrative approach to health care for GPs.
- Her contribution to the *‘Guide to Pain Management in the Low Resource Setting’* sponsored by the International Association for the Study of Pain (IASP) for 3rd world distribution.
- Online pelvic pain learning modules for The Royal Australian and New Zealand College of Obstetricians and Gynaecologists, and Womens Health Queensland Wide videostreaming patient presentations.
- Magazine articles for RANZCOG Magazine, Asia Pacific Endometriosis Alliance, Endometriosis New Zealand, Womans’ Day, Cosmopolitan, Healthy Times, PakMag, TV Soap, New Idea, and Oriental Magazine.
- Media interviews on National and State, ABC and Commercial, television and radio, providing easily understood messages to women and families throughout Australia.

Susan has presented at academic conferences and meetings in Australia and the Asia Pacific Region, delivering pragmatic solutions to pelvic pain to her audiences. Her awareness that chronic pelvic pain requires more than the best surgical and medical expertise can offer, and her dedication to easing suffering and improving health outcomes for all Australian women, was acknowledged recently by her election to Fellowship of the Faculty of Pain Medicine in 2010.

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PROFESSOR THIERRY GEORGES VANCAILLIE MD, FRANZCOG, FFPMANZCA
GYNAECOLOGIST, LAPAROSCOPIC SURGEON, SPECIALIST PAIN MEDICINE PHYSICIAN

Professor Thierry Vancaillie is a gynaecologist in Sydney, Australia specialising in the treatment and management of pelvic pain.

Current positions:

- Clinical Professor of Gynaecology University of New South Wales 2009 – current
- Staff Specialist, Royal Hospital for Women, Sydney 2009 – current
- Specialist Pain Medicine Physician 2010 – current
- Director, Women's Health and Research Institute of Australia

Born and educated in Belgium, Thierry had an interest and skill in surgery and micro-surgery from the outset of his career. Since his internship in 1979, Thierry has published 71 papers, has contributed to 41 book chapters and has written three books. He has also presented 26 abstracts at conferences around the world and numerous poster presentations have been accepted. As well, Thierry has 9 surgical instrument patents.

Thierry has received grant support from Rotary, Karl Storz and an International Assistant Fund for teaching and research purposes. He successfully obtained an RO-1 grant from the National Institute of Health (NIH) (USA) while working at the University of Texas Health Science Centre in San Antonio, (UTHSCSA) Texas. He was awarded the George Mitchell award for excellence in teaching by the department of Obstetrics and Gynaecology (O&G) at the UTHSCSA in 1986 and again in 1990.

Thierry has Chaired and Co-Chaired World Congresses in the USA, France, Germany and has been on the organising committee for many international meetings. He has been invited instructor at surgical workshops in the USA and Europe and is an ad hoc reviewer of professional journal publications.

Thierry's interest in redefining best practice treatment has advanced in recent times as his interest in improving outcomes for women with pelvic pain has developed. He has an acute understanding of anatomy and the human response to surgical and medical treatments alone or combined. For best health outcomes, he is now an advocate of a multi-disciplinary holistic approach to the treatment of pelvic pain. He has introduced this concept to his practice in Sydney and is a staunch promoter of this treatment methodology.

Thierry was elected to Fellowship of the Faculty of Pain Medicine of the Australian and New Zealand College of Anaesthetists in 2010.

Contact Thierry: thierryvancaillie@mac.com

ADVISORY GROUP

<p>DR JILL BENSON MBBS, DCH, FACPsychMed, MPH</p>	<p>General practice for 30+ years with special expertise in Aboriginal and Refugee Health. Director of Health in Human Diversity Unit in Discipline of General Practice at the University of Adelaide. World Health Organisation (WHO) Consultant in Vanuatu.</p>
<p>DR PENNY BRISCOE MBBS, FANZCA, FFPMANZCA</p>	<p>Past Dean, Faculty of Pain Medicine, Australian and New Zealand College of Anaesthetists. Head of Unit, Pain Management Unit, Royal Adelaide Hospital, SA</p>
<p>MS LESLEY BRYDON BPharm, MAICD, FPRIA</p>	<p>Lesley Brydon is a pharmacist and experienced consumer advocate. She is CEO of PainAustralia, a national network of healthcare and consumer organisations which aims to improve services for people living with pain, through implementation of the National Pain Strategy.</p>
<p>DR MEREDITH CRAIGIE MBBS, B Med Sc, MM(PM), FANZCA, FFPMANZCA</p>	<p>Staff Specialist, Pain Management Unit, Royal Adelaide Hospital. Staff Specialist, Anaesthesia and Pain Medicine, Flinders Medical Centre, Adelaide, South Australia. Chair Faculty of Pain Medicine Examination Committee and the Paediatric Pain Working Party.</p>
<p>PROFESSOR IAN FRASER AO MD, BSc (Hons), FRANZCOG, FRCOG, CREI</p>	<p>Professor in Reproductive Medicine, University of Sydney. Reproductive Endocrinology and Infertility sub-specialist at the Royal Prince Alfred Hospital, Sydney. Past-President of RANZCOG. Honorary Secretary of FIGO. Foundation Vice-President and Honorary Life Member of AGES. Honorary Life Member of FSA.</p>
<p>Ms STEPHANIE GASKELL BDN, APD, AN</p>	<p>Dietician with specialty in treating those with Coeliac Disease, Irritable Bowel Syndrome (IBS), Inflammatory Bowel Disease (IBD), Low FODMAP Diet, Sports Nutrition. Stephanie is also a Personal Trainer. Her practice is 'ShepherdWorks', Adelaide.</p>
<p>DR LOUISE HULL BSc, MBChB, PhD, FRANZCOG</p>	<p>Senior Lecturer University of Adelaide, Head of Endometriosis research Centre, University of Adelaide, Consultant Specialist at Women's and Children's Hospital Adelaide.</p>
<p>DR TAL JACOBSON MA, MRCOG, FRANZCOG</p>	<p>Staff Specialist Mater Mother's Hospital, Brisbane.</p>
<p>Ms SHERIN JARVIS B App Sc (Physio), C Acup, C Cont Prom, C Urodynamics</p>	<p>Conjoint Lecturer UNSW, Sydney, NSW. Clinical Specialist Pelvic Physiotherapist Royal Hospital for Women, Sydney, NSW. Director, Women's Health and Research Institute of Australia.</p>
<p>DR PETER MAHER MBBS, MRCOG, FRANZCOG, FRCOG</p>	<p>Assoc.Professor, Director, Department of Endosurgery, Department of Obstetrics and Gynaecology, University of MLB. Mercy Hospital for Women, MLB. Co-founder Endometriosis Care Centre of Australia.</p>
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APPENDIX VI

Grants

The Pelvic Pain Project initiative received no external grants from organisations, industry, other group or individual. The recommendations were developed through an independent process involving health professionals and consumers. Advisors and reviewers gave their time voluntarily.

Conflict of Interest

The intellectual property of the '*me*' adolescent endometriosis educational program in schools is owned by Deborah Bush in an arrangement with Endometriosis New Zealand. No personal royalties have been received from the program.

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