Public Health Association of Australia
submission on the development of a
National Action Plan for Endometriosis

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28 May 2018
# Contents

Preamble ........................................................................................................................................... 3

The Public Health Association of Australia ......................................................................................... 3

Vision for a healthy population ......................................................................................................... 3

Mission for the Public Health Association of Australia .................................................................. 3

Introduction ....................................................................................................................................... 3

PHAA Response to the consultation questions .................................................................................. 4

Question 9. The structure of the Plan is appropriate and easy to follow ........................................ 4

Part 1. Why endometriosis matters, call for action, foundation for action ...................................... 4

Part 2. What we want to achieve ....................................................................................................... 4

Part 3. Partnerships ........................................................................................................................... 5

Priority area 1 – Awareness and education ....................................................................................... 5

Priority area 2 – Clinical management and care ................................................................................ 5

Priority area 3 – Research .................................................................................................................. 6

Section D – Achieving Progress ........................................................................................................ 6

Section E – Framework for Action – Priority area 1 ........................................................................ 6

Section E – Framework for Action – Priority area 2 ........................................................................ 7

Section E – Framework for Action – Priority area 3 ........................................................................ 7

Section F – Implementation partners ............................................................................................... 7

Conclusion ......................................................................................................................................... 8

References ......................................................................................................................................... 9
Preamble

The Public Health Association of Australia

The Public Health Association of Australia (PHAA) is recognised as the principal non-government organisation for public health in Australia working to promote the health and well-being of all Australians. It is the pre- eminent voice for the public’s health in Australia. The PHAA works to ensure that the public’s health is improved through sustained and determined efforts of the Board, the National Office, the State and Territory Branches, the Special Interest Groups and members.

The efforts of the PHAA are enhanced by our vision for a healthy Australia and by engaging with like-minded stakeholders in order to build coalitions of interest that influence public opinion, the media, political parties and governments.

Health is a human right, a vital resource for everyday life, and key factor in sustainability. Health equity and inequity do not exist in isolation from the conditions that underpin people’s health. The health status of all people is impacted by the social, cultural, political, environmental and economic determinants of health. Specific focus on these determinants is necessary to reduce the unfair and unjust effects of conditions of living that cause poor health and disease. These determinants underpin the strategic direction of the Association.

All members of the Association are committed to better health outcomes based on these principles.

Vision for a healthy population

A healthy region, a healthy nation, healthy people: living in an equitable society underpinned by a well-functioning ecosystem and a healthy environment, improving and promoting health for all.

Mission for the Public Health Association of Australia

As the leading national peak body for public health representation and advocacy, to drive better health outcomes through increased knowledge, better access and equity, evidence informed policy and effective population-based practice in public health.

Introduction

PHAA welcomes the opportunity to provide input to the development of a National Action Plan for Endometriosis. The reduction of social and health inequities should be an over-arching goal of national policy and recognised as a key measure of our progress as a society. The Australian Government, in collaboration with the States/Territories, should provide a comprehensive national cross-government framework on promoting a healthy ecosystem and reducing social and health inequities. All public health activities and related government policy should be directed towards reducing social and health inequity nationally and, where possible, internationally.
PHAA Response to the consultation questions

Question 9. The structure of the Plan is appropriate and easy to follow

PHAA supports the use of figures and quotes from women which are visually helpful and serve to bring women’s voices into the document.

Part 1. Why endometriosis matters, call for action, foundation for action


Part 1 provides useful context and background for the Plan, but some areas could be improved.

The introduction should include further acknowledgement of the unrelenting advocacy led by patients in recent years should be included in this section as to how the Plan has come into being. Without these women being driven by severe physical and psycho-social impacts to their lives, it is doubtful that this would have made it onto the national agenda. Further contextualising of the current gap between the impact on women’s lives and current levels of investment into research, and pre-conceived ideas around women’s pain that have led to the current environment surrounding endometriosis would be helpful. The rest of the document makes reference to achieving respectful interactions but context and background understates the extent to which women have experienced lack of respect, belief of their pain and the nature of the debilitation.

The language of women centred care, shared decision making and the co-production of health care and services is lacking in this document. There is a need to acknowledge the need for different approaches to care depending on the life course from adolescence to peri menopause.

On p2, the references to UK and Ireland, and NICE guidelines noted as a potential model for guidelines development are useful. PHAA suggests that a reference to Canadian guidelines (https://sogc.org/wp-content/uploads/2013/01/gui244CPG1007E.pdf) would be a helpful addition.

Given that one of the significant effects of endometriosis is compromised fertility, PHAA suggests emphasising the impact of endometriosis on fertility, and therefore, on the capacity and problems faced by up to 1 in 3 women with endometriosis who encounter fertility problems, to conceive a healthy baby.1,2

On page 2, the Call for Action/Public awareness and education may be usefully amended to:

“...as well as communication regarding its potential detrimental effects on women’s fertility and on social and economic participation”.

Part 2. What we want to achieve


PHAA supports the inclusion high priority placed on awareness and education, and suggests that a range of organisations supporting women’s health are involved in the development and delivery of education and awareness raising activities. For example, tailored information and education initiatives specifically addressing fertility should include that endometriosis can cause fertility issues, but that reliable contraception is still needed to avoid unplanned pregnancy. The ongoing involvement of women who have experienced endometriosis in all phases of development and delivery is vital.
In clinical management and care, PHAA suggests using the term ‘priority populations’ rather than ‘vulnerable population groups’. While PHAA supports a focus on clinical management and care, it is not clear how psycho-social support and care fits with the priorities. It would be helpful to clarify this in the Plan.

Part 3. Partnerships

Questions 14-15. Does Part 3 outline that strong partnerships between government, patients, advocates, healthcare professionals and industry are necessary to implement the actions identified in the Plan? Explain.

To be inclusive of gender diversity, PHAA supports the language of “patients with endometriosis” rather than “women and girls with endometriosis”. An increased focus on partners and carers may be useful.

Similarly, while researchers and research institutions are mentioned as implementation partners, there is a need to drive research such as PhD research into this area to grow the base of emerging researchers in this area, as well as building the literature and evidence base around endometriosis. It would be helpful to highlight this more in the Partnerships section to better align with Research being a priority area in the Plan.

The Australian Digital Health Agency may be a potential partner for example in the Research priority area data mining and linkage.

Priority area 1 – Awareness and education

Questions 16-18. Does the information in Priority area 1 adequately address the key areas to improve awareness and education? Explain. Is there anything missing or should anything be changed?

PHAA supports the emphasis on school education as being an important pathway for awareness and education in this area. However, the role of the technical and further education and university sector is unclear in the current draft.

The family, community, social services sectors may need to be considered to better incorporate the needs of patients who are in out of home care or those with disabilities.

Priority area 2 – Clinical management and care

Questions 19-21. Does the information in Priority area 2 adequately address the key areas to improve outcomes for patients with endometriosis? Explain. Is there anything missing or should anything be changed?

In the current draft, the impact of endometriosis on sexual health is not clearly stated both in terms of provider information and care to be provided.

The draft should clarify whether clinical and care pathways will be stand alone or integrated into the pathway plans developed with local health services e.g. HealthPathways through PHNs.

Some of the areas covered under Priority Area #2 will need to be supported by research. This overlap is not explicitly referred to in draft Plan. For example, 3.1 “Devise and promote a single, standardised and easily accessible tool to aid or precede diagnosis...”.

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Priority area 3 – Research

Questions 22-24. Does the information in Priority area 3 adequately address the key areas for research? Explain. Is there anything missing or should anything be changed?

PHAA strongly supports the emphasis on research into endometriosis. There are some additional areas which PHAA suggests would be helpful additions:

- quality health service delivery including coordinated care to manage endometriosis
- the relationships between endometriosis and endometrioid and clear cell epithelial ovarian cancers
- relationship with legislation and industry e.g. classification of endometriosis as disability and context for employment and study

As the Plan notes, knowledge about the epidemiology of endometriosis and the burden of disease is an area of need for research now and into the future. PHAA supports growing investment in this field.

Section D – Achieving Progress

Questions 25-27. Does the information in Section D adequately provide high level guidance for the planning and development of policies and actions related to endometriosis and pelvic pain? Explain. Is there anything missing or should anything be changed?

PHAA strongly supports the inclusion of criteria for assessing progress in the Plan. The indicators chosen must be both measurable and informative in terms of where additional investment is needed and to identify where approaches to health promotion have been unsuccessful, and how to do better. For example, with investment being made into school education and awareness programs, rather than simply assessing implementation of the programs, an assessment of students’ knowledge and awareness at baseline and later would be a useful measure. Similarly, an indicator that provides insight into the level of consumer engagement in the development of products and processes would be useful.

In Table 1, criteria 2, it would be helpful to clarify what is meant by “base level”? How will this be measured? Will there be baseline random assessment in Year 1 and Year 5 to observe difference?

Section E – Framework for Action – Priority area 1

Questions 28-30. Does the information in Priority area 1 of the Framework for Action provide adequate actions for endometriosis community awareness campaigns? Explain. Is there anything missing or should anything be changed?

Awareness and education

The Plan should explicitly state the process of co-designing education materials, self-management and shared decision-making tools with patients. This includes the need for thorough piloting to ensure comprehensibility, usability, acceptability and feasibility.

Special consideration is required for patients in out of home care and patients with disabilities. Drawing attention to the education of foster parents, carers and professionals in family and community services, would be a useful addition to this section.

It would be helpful to specifically reference the need for commitment from partners to ensure that developed resources are prioritised and disseminated.
Section E – Framework for Action – Priority area 2

Questions 31-33. Does the information in Priority area 2 of the Framework for Action provide adequate actions to ensure endometriosis is recognised, care standards are developed, and care options are accessible? Explain. Is there anything missing or should anything be changed?

Clinical management and care

Clinical management and care will require the development of continuing professional development modules for professional associations (RCGP, RANZCOG, CAN etc). Communities of practice around endometriosis should be created so clinicians can share information and support each other in their practice.

PHAA recommends that professional associations, consumers and the National Health and Medical Research Council be involved in the development and endorsement of clinical guidelines and clinical care standards to promote integrative care for all stages of the care pathway.

It would be helpful for some other resources to be referenced here including:

- other guidelines such as the Society of Obstetricians and Gynaecologists of Canada (https://sogc.org/wp-content/uploads/2013/01/gui244CPG1007E.pdf)
- the Endometriosis and Infertility consensus statement from ACCEPT (Australasian CREI Consensus Expert Panel on Trial evidence) as movement towards agreement among sub-specialists in this area.

Some critical elements of clinical management and care could be better highlighted in the Plan. Shared decision making should be emphasised to achieve best quality clinical management and care for patients. Attention needs to be drawn to the pre-conception care and planning needs of women with endometriosis. It will be important to recognise where existing work has been done around pathways, and to work with PHNs and other partners to avoid duplication.

Section E – Framework for Action – Priority area 3

Questions 34-36. Does the information in Priority area 3 of the Framework for Action provide adequate actions to enable endometriosis research? Explain. Is there anything missing or should anything be changed?

Research

Research should be conducted into the health system response to endometriosis to determine if the response is appropriate, and what care, services and information need to be adopted/modified and scaled up.

Section F – Implementation partners

Questions 37-39. Does the information in Implementation Partners of the Framework for Action adequately summarise the key partners required to enable the successful implementation of the actions? Explain. Is there anything missing or should anything be changed?

The Public Health Association of Australia (PHAA) and the Australian Sexual Health Alliance (ASHA) should be included in this list to further enable advocacy and the engagement of diverse professionals in education, policy development and awareness raising.
Conclusion

PHAA supports the broad directions of the draft National Action Plan for Endometriosis. This is an important area of health which has long been neglected. A strong National Action Plan with an emphasis on research, education and clinical care will provide a pathway for better recognition, understanding and care of this condition. The Plan should emphasise the important role patients have played in getting a Plan, and continue their involvement through consultation in resource development and research.

The PHAA appreciates the opportunity to make this submission and the opportunity to contribute to the National Action Plan.

Please do not hesitate to contact me should you require additional information or have any queries in relation to this submission.

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28 May 2018
References