

30 May 2018

Ms Marcia Grant
A/Director,
Preventative Health Policy
Population Health & Sport Division
Department of Health
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Dear Ms Grant,

Thank you for the opportunity to comment on the Australian Government's *National Action Plan for Endometriosis* (the Plan). Endometriosis impacts the lives of many women and their families, and is a cause of significant morbidity. The Royal Australian College of General Practitioners (RACGP) therefore welcomes the Government's focus on this area and supports many of the initiatives outlined in the Plan.

The burden for the detection and referral of endometriosis depends largely on general practitioners (GPs) who are key to the early diagnosis and management of women with this condition. It is important that the RACGP is involved and consulted in the process going forward to ensure the strategies are appropriate and realistic for general practice.

The RACGP provides suggestions below to support further development of the Plan.

Education and implementation

- The RACGP supports the provision of further education, particularly for contemporary treatment pathways. Ideally this should be an embedded approach within general practitioner lifelong learning, which should be done in consultation with the RACGP education and professional development programs.
- One of the key approaches to the treatment of endometriosis is the use of long acting reversible contraception, especially levonorgestrel intrauterine systems. GPs are critical to increasing utilisation of these methods, and require better support and opportunities to both be trained in insertion and to sustain this practice.
- The RACGP supports the development of public awareness campaigns. As part of the awareness campaign, care should be undertaken not to precipitate fear in the community which may in turn lead to over-investigation, over-referral and overtreatment (discussed further under overdiagnosis overleaf).

Diagnosis

- It is important to include in the Plan an explanation as to how the condition can present. One of the difficulties of diagnosing endometriosis is that its "red flags" can present in subtle but common ways, and can sometimes be construed as 'normal' by both the patient and the doctor. Clear evidence based guidance needs to be developed to assist GPs in the early diagnosis and control of the condition.

- The consequences of undiagnosed endometriosis can have severe life impacts for women and their families. This includes chronic pain and infertility. Psychological support should be made available under Medicare for women experiencing fertility issues or who have chronic pain, both of which can be major sources of anxiety and depression for endometriosis patients.

Overdiagnosis

- Overdiagnosis can cause harm and waste finite health resources. The RACGP has concerns regarding the potential for overdiagnosis and overtreatment, believes these issues should be given careful consideration by those developing the Plan.
- The Plan should advocate for early 'suspected diagnosis', with the appropriate first step being trial of treatment, instead of an emphasis on early definitive diagnosis through invasive and expensive laparoscopy and biopsy procedures. We need to be cognisant of such procedures being done unnecessarily, leading to long waiting lists in the public system, or financial burden through the private system. The Plan should include strategies to address these issues.
- The development of patient information would help GPs explain the steps to be taken in endometriosis treatment in consultation with their patient. This information should include: possible complications which may arise from procedures and investigations not supported or routinely performed.

Research

- There is a need for more research into endometriosis and particularly at the general practice level. Currently, there is no clear picture of how women present in general practice, nor the prevalence of the condition, or how it is managed. These basic descriptors, together with trials and interventions aimed at improving the diagnosis and management of endometriosis where it first presents in general practice, is urgently needed.
- Data captured from existing programs (or having a validated GP research program to evaluate data from a GP perspective) will assist in improving diagnosis and management. This could include data on current rates of gynaecological laparoscopy (including the positive and negative rates of laparoscopy) and rates of medication use for endometriosis.

General comments

- GPs help and support women through the diagnosis and management of endometriosis. *Objective 3, as part of Figure 5: Objectives of the first National Action Plan for Endometriosis* (page 7), suggests that health practitioners 'should take pelvic pain seriously and treat women with dignity'. As a profession, we are committed to do this for all our patients, and we suggest removing this statement.

Thank you again for the opportunity to comment on the Plan and we welcome future opportunities for engagement on the issues discussed in this submission.

Yours sincerely



Associate Professor Charlotte Hespe
Vice-President