



22 September 2016

Ms Jeanette Radcliffe  
Committee Secretary  
Senate Standing Committees on Community Affairs  
PO Box 6100  
Parliament House  
Canberra ACT 2600

Dear Ms Radcliffe

Thank you for the invitation to submit to the Senate Community Affairs Legislation Committee inquiry into the National Cancer Screening Register Bill 2016 and related Bill. This letter is our submission; we would also welcome the opportunity to appear at a public hearing to elaborate on our position and recommendations.

Cancer Council is the largest nongovernment cancer organisation in Australia and the only independent NGO that has been formally involved in the development and promotion of all of Australia's cancer screening programs since their inception. Indeed, we were a vocal, independent advocate for the establishment of all three programs before their introduction.

Cancer Council Australia calls on the Federal Parliament to pass the bills expeditiously. The bills are essential legislative enablers for:

- the ongoing expansion and improved effectiveness of Australia's National Bowel Cancer Screening Program (NBCSP); and
- the transition to a new, improved system for cervical cancer screening in Australia, referred to as the National Cervical Screening Program Renewal (the Renewal).

The clinical effectiveness of these programs is dependent on participation rates and the programs' capacity to expand and improve. More eligible people screening, and program improvements to help optimise the potential to detect and successfully treat cancers early, will mean more lives saved.

The net result of undue, protracted scrutiny of the bills enabling program expansion and improvement could in effect be the unnecessary loss of Australian lives.

Concerns about issues such as privacy are often raised when a major public health initiative, underpinned by the management of population-level health data, is introduced or reformed. While such concerns might in some cases be in the public interest, the core priority of any Parliament should be the saving or extending of its constituents' lives. To this end, concerns about the bills should not have a flow-on effect of delaying the advancement of the NBCSP or the Renewal.

While issues related to privacy or data integrity must be taken seriously, in our view these matters could be addressed through non-legislative means such as ongoing scrutiny of the programs in practice or alternative public policy instruments such as regulatory reform. Importantly, such efforts would not pose risks to delaying advancement of these vital programs, while at the same time providing privacy protection to the Australian public.

Our independent legal advisers have looked at the bills and observed no areas for concern in relation to public policy and the public interest. We therefore recommend that this committee urges both Houses of Parliament to pass the bills expeditiously.

In the lead-up to the 2016 federal election, Cancer Council Australia drew on pre-publication research and analysis showing that a 60% participation rate in the NBCSP (current participation is 37%) by 2020 will prevent 84,000 premature bowel cancer deaths in Australia by 2040.<sup>1</sup> Delays to the passage of the bills could delay essential program improvements needed to increase participation, such as an enhanced screening pathway and extensions to the screening age cohort (scheduled to take effect from 1 January 2017). Moreover, the history of the NBCSP shows that exaggerated concerns about any aspect of its integrity discourages participation – compounded by an overall lack of bowel cancer awareness. This is sadly at odds with the evidence showing that optimal bowel cancer screening (apart from tobacco control) is the single most effective intervention available to the Australian Government to reduce cancer death and disease burden.

Flow-on effects from delayed passage of the screening register bills could also risk compromising the introduction of the cervical screening Renewal, scheduled for May 2017. The Renewal will be a major change in primary screening practice from a two-yearly Pap test regime to a five-yearly human papillomavirus test. Modelling shows that the change will reduce the number of cervical cancer cases in Australia by at least 20%.<sup>2</sup> Again, ensuring that this lifesaving changes is legislatively enabled should be the first priority of Australia's Federal Parliament.

Based on our extensive experience with, and expertise in, these programs, and the epidemiological evidence, it is clear to us that a better use of the Federal Parliament would be to consider ways to increase program participation – and expeditiously adopt evidence-based program enhancements, such as the new integrated screening register.

Thank you again. We look forward to opportunities to discuss our advice further.

Yours sincerely

Professor Sanchia Aranda  
Chief Executive Officer

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<sup>1</sup> Lew, St John, Macrae, Bampton, Emery, Ee, He, Grogan, Caruana, Greuter, Coupe, Canfell. *Evaluation of the benefits, harms and cost-effectiveness of alternate colorectal cancer screening strategies in Australia*. 2016, pre-publication.

<sup>2</sup> Cancer Council Australia Cervical Cancer Screening Guidelines Working Party. *National Cervical Screening Program: Guidelines for the management of screen-detected abnormalities, screening in specific populations and investigation of abnormal vaginal bleeding*. Cancer Council Australia, Sydney 2016.