



22 September 2016

**The Senate Standing Committee on Community Affairs**

***National Cancer Screening Registry Bill 2016.***

This submission addresses the issue of how cancer screening programs are most effectively run if they are to fulfil their clinical and public health roles.

I am a public health researcher with over 30 years involvement in disease prevention, and over 600 publications in health and medical research. My career has involved research into both cancer and infectious diseases, initially with the International Agency for Research on Cancer in Lyon (1983-89) and subsequently at UNSW. I contributed to the first epidemiological studies that confirmed the role of human papillomavirus in causing cervical cancer in the 1980s, and more recently have been one of the lead investigators in the world-first studies from Australia that demonstrated the population effectiveness of the HPV vaccine in preventing infection. I have been a member of numerous government advisory committees in public health, and have recently been appointed to the ATAGI Working Party on HPV.

It was with considerable surprise and some concern that the public health community was informed several months ago of the Australian Government's decision to award the major contract for the new national cancer screening registry to a commercial entity. Public health researchers and practitioners strongly supported, and indeed had long argued for, an integrated national system to strengthen both the clinical and public health dimensions of screening. However, the ideal model for a national screening registry would have built on the successful features of the individual state-based systems that had been operating for over two decades, and had learned many valuable lessons in the process. The concern in the public health community has arisen because it is not at all clear that a national registry under the control of a commercial provider is well positioned to draw on the long experience of the jurisdictional registries. Some of the key issues are as follows:

1. A screening registry at its core is a tool for supporting clinicians and patients, to maximise the likelihood that screening will be offered to eligible individuals, that it will be taken up, and that the necessary processes of follow up and recall are in place. As such, its design and conduct require extensive experience in the clinical steps involved. The data management aspect of a registry can greatly facilitate its functioning, but will be of no use if the clinical fundamentals are not understood.
2. There is a great deal of trust involved on behalf of both clinicians and patients in the use of an external registry to support clinical practice in screening. This trust relates to both the clinical expertise referred to under (1) as well as the key requirement for records to be fully protected in regard to privacy and other potential misuses of data. The state registries had built up a level of trust that must be jealously guarded



if a national approach is to succeed. One key feature of the trust was the understanding that the registries were not-for-profit entities, a situation that is no longer the case.

3. The uptake of cancer screening remains uneven in Australia, with under-screening in several populations at risk of preventable cancers. For example, it is well recognised that the higher rates of cervical cancer in Aboriginal women compared to non-Aboriginal women are largely due to lower attendance for screening. A key role of the registries has been to conduct ongoing analyses, working in collaborative partnerships with academic groups, community organisations and other key stakeholders, to identify these screening gaps and investigate strategies for closing them. Registries joined these partnerships because they saw themselves as part of a broader community united in the cause of cancer control. A commercial registry operator will claim to hold these values but its ability to enter into such collaborations will inevitably be influenced by cost and profit considerations.

These issues must be properly addressed if the national approach to screening is to generate a material advance over the system that has been in place so far. The risk is that we will have replaced an imperfect but functional system with one that has lost the trust of its clients, and therefore can not adequately serve the purpose for which it has been established.

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