



# Submission to Senate Inquiry

*National Cancer Screening Register Bill 2016  
and National Cancer Screening Register  
(Consequential and Transitional Provisions) Bill  
2016*

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# Submission to Senate Inquiry - National Cancer Screening Register Bill 2016 and National Cancer Screening Register (Consequential and Transitional Provisions) Bill 2016

## Purpose

The purpose of this submission is to provide the views of Pathology Australia (PA) and its members on the National Cancer Screening Register Bill 2016 and National Cancer Screening Register (Consequential and Transitional Provisions) Bill 2016.

PA notes there are no publically available terms of reference for this inquiry.

As such, our submission focuses on:

- The essential role of Pathology in the transition to a renewed National Cervical Screening Program;
- the role that Pathology plays in the diagnosis of cervical cancer, and the significant changes to the Pathology workforce in continuing to play this role following the Cervical Cancer Screening Renewal in May 2017;
- PA's support for no delay of the implementation of changes to the National Cervical Screening Program; and
- PA's support for the National Cancer Screening Registry through the mechanisms of Parliament.

## About PA

Pathology Australia is the peak body representing private pathology practices in Australia. PA has membership that covers all types of pathology practices from large to small practices as well as generalised to specialised pathology practice.

## Role of Pathology

Pathology is a referred specialist medical service which provides a fast, efficient, high quality, relatively inexpensive diagnostic support service for GPs and other specialist medical providers. In round numbers, there are approximately 40 million pathology referrals each year for approximately 90 million tests with total pathology expenditure through the MBS of \$2.5 billion per annum.

The literature shows that 70% of medical treatment decisions rely on pathology results<sup>1</sup> and 100% of cancer diagnoses are supported by pathology results. High quality health care is impossible without high quality pathology.

There is a very strong quality framework underpinning pathology through National Pathology Accreditation Advisory Committee (NPAAC) /National Association of Testing Authorities (NATA) guidelines<sup>2</sup> which entail frequent laboratory assessments covering all areas of laboratory operations. The resulting high standards maintained by Australian pathology laboratories has

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<sup>1</sup> "Clinical Laboratory Tests: Which, why and What do results mean?" Wians, Frank. LabMedicine. Feb 2009, Vol 40 (2): 105-113

<sup>2</sup> Department of Health, National Pathology Accreditation Advisory Committee (NPAAC), accessed 22 September 2016, <<http://www.health.gov.au/npaac>>  
National Association of Testing Authorities, Australia (NATA), 2016, accessed 22 September 2016, <<http://www.nata.com.au/nata/>>

meant the sector has avoided the systemic failures and resulting scandals seen in other countries. These stringent requirements while critical to the quality of pathology services ensure effective and efficient delivery of pathology services at a high overhead cost to the sector.

## **Background**

### ***Cervical Screening in Australia***

Australia has an enviable record in fighting cervical cancer. A record that has been achieved through the introduction of an organised and quality controlled cervical screening program which has been in place since 1991.

This program is based on a Pap smear test offered to women every two (2) years. It is supported by state based Pap Smear Test Registers which hold screening and follow up test information as well as providing reminders for screening tests to women when they are due.

Since 1991 there have been significant advances in cervical cancer knowledge, with the identification of the Human Papillomavirus (HPV) virus as the causative agent of cervical cancer and the subsequent development of the HPV vaccine. Social changes have also occurred. Australia's population is now more transient and technological advances see Australian women now taking an increased interest in, and responsibility for, their own health outcomes.

The Renewal of Australia's National Cervical Screening Program, which gained Medical Services Advisory Committee (MSAC) approval in April 2014, is another world leading initiative timed to build on the benefits of Australia's school based HPV vaccination program which began 2007.

As more and more women in the Australian screening population are vaccinated it is now possible to introduce a more sensitive and less frequent test than the two yearly Pap smear.

From May 1<sup>st</sup> 2017, the HPV primary screening test will be offered to Australian women aged between 25 and 74 every five (5) years. The implementation of this new cervical screening program was approved by AHMAC in September 2014.

### ***Transition – Renewal Program for Cervical Screening***

The process of transition of the National Cervical Screening Program has already begun. In this case, Australia is leading the world in the development of a more relevant and appropriate Cervical Screening program. Many other nations are watching our implementation and transition to the new National Cervical Screening Program, watching for lessons learned and implementation issues. The Pathology sector supports the move to the new National Cervical Screening Program – the Renewal Program – and supports the evidence base for the move to new HPV testing. Pathology Australia has supported this change in Government policy publicly<sup>3</sup>.

The Pathology sector has been planning the move to the National Cervical Screening Program for the last two years. This has been a time of upheaval as the workforce mix changes within Pathology laboratories.

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<sup>3</sup> Pathology Australia 2015, *Pathology Supports Changes to Cervical Screening*, media release, accessed 22 September 2016, <<http://www.pathologyaustralia.com.au/2015/09/12/cervical-screening/>>

Pathology Australia 2016, *Cancer Register Right for Women*, media release, accessed 22 September 2016, <<http://www.pathologyaustralia.com.au/2016/08/31/cancer-register-right-for-women/>>

The Pap smear is a labour intensive pathology test requiring highly skilled scientists (called cytologists) to examine cellular material under a microscope. The new HPV test is much less labour intensive and although the requirement for some cytologists will remain, the majority of cytologists currently screening Pap tests will no longer be required. These scientists have had to face the painful reality of having to transition to alternate careers and the numbers of cytologists currently in paid employment is dropping significantly as a consequence.

This has resulted in an ever decreasing cytology workforce which no longer has the ability to adequately support the current program and the turnaround time for Pap smears in Australia is growing rapidly as a result.

***Recommendation 1:***

***Pathology Australia strongly recommends there can be no delay to the commencement of the new National Cervical Screening Program on May 1<sup>st</sup> 2017.***

***One National Cancer registry***

The success of the new cervical screening program relies on the establishment of a modern and robust National Cancer Screening Register (NCSR). The register will be required to use the latest technology, security and confidentiality mechanisms to bring together relevant clinical and demographic data currently spread across multiple state based registers, which are incapable of supporting the National Cervical Screening Program. The NCSR will provide a fully comprehensive screening database which will also incorporate HPV vaccination status and colposcopy results providing a scalable technology platform for Australia's future needs in the area of women's health.

The clear benefit of the Register is that being able to collect and collate cases on a national scale will over time empower efforts to combat cervical and bowel cancer. It will also act as the key reminder tool for patients on the essential national, evidence based screening programs for both bowel and cervical cancer. It will underpin Australia's approach to population based screening.

***Recommendation 2:***

***Pathology Australia supports the establishment of the NCSR, an essential component of the National Cervical Screening Program which will positively impact the health of all Australians.***

After a lengthy and comprehensive tender process implemented by the Department of Health, the contract for the NCSR (which will cover not only cervical cancer screening but also bowel cancer screening) was awarded to Telstra Health. It is Pathology Australia's understanding that a competitive process was implemented according to the Australian Government's procurement guidelines. It is also our understanding and expectation that stringent rules around patient privacy are explicit within this contract and the associated legislation currently before Parliament that comply with the Australian Government's privacy and security requirements.

Telstra Health is a 'for profit' organisation. Pathology Australia is clear in our view that this does not exempt them from the privacy and legislative requirements for the implementation of this essential component of the Renewal program. A for profit organisation should and would take these issues just as seriously as a 'not for profit' organisation. Indeed it should be clearly recognised that most pathology providers, gynaecologist and GP practices involved in cervical screening could themselves be defined as 'for profit' organisations all of which have access to and appropriately handle sensitive and private clinical and demographic data. This is not new in

the management of health care in Australia with our mix of private and public health services, working in partnership with Government.

Pathology providers will be required, in fact mandated, to send patient demographic and test data to the register and in turn will receive information on the patient's relevant screening, diagnostic and vaccination history. This pathology data is the basis of populating the Registry. Without this information it will be impossible for pathology companies to apply the correct clinical recommendations relied on by clinicians for diagnosis of disease. Without this database, the Renewal program will stall, not meet the identified timelines of May 2017 and Australia's transition to the latest evidence based management of women's cervical screening will be significantly disadvantaged. This could result in adverse health outcomes for Australian women including delays in the diagnosis of cervical cancer and delays in receiving essential care - something that has been managed appropriately for the past 25 years. The critical principle of delivering a single national database for the management of the population health for Australian women prior to the cervical cancer renewal in May 2017 should not be jeopardised by the debate regarding the need for appropriate patient privacy and confidentiality – a fact that is not in dispute and has been adequately addressed in the proposed Legislation.

***Recommendation 3:***

***Pathology Australia strongly supports the necessary patient privacy and confidentiality, which we believe to be encompassed in the National Cancer Screening Registry Bill 2016 and the National Cancer Screening Register (Consequential and Transitional Provisions) Bill 2016, and supports its passage through Parliament without delay.***

***Recommendation 4:***

***To delay the implementation of the National Cervical Screening Program post May 2017, of which the Registry is an essential component, will be significantly detrimental to women's health care in Australia.***

***Other cancer screening programs***

As pathology providers will be mandated to provide patient data to the NSCR, providers have been working for some time on the technology transition to one, national database. This work has been ongoing within the Pathology sector for some time and involves ensuring providers meet all data security and confidentiality standards and frameworks currently seen as best practice in Australia. The NSCR will be no exception.

In addition, the efficiencies for the Pathology sector of reporting to one database for the National Cervical Screening Program are substantial, despite the initial investment in technology rebasing, but longer term, there are significant efficiencies for the sector should other population health cancer screening programs be added to the NSCR in the future. This significantly reduces the red tape for the Pathology sector, matching the technical capabilities of one cancer screening registry to internal proprietary pathology information systems.

***Penalties for Breaches***

A key issue raised has been the process of the declaration of, and fines for data access breaches.

Whilst Pathology Australia would not expect a significant number of confidential data breaches and unauthorised access of confidential records, human nature would expect there to be a small

number. This would occur in both the public and private sector, not for profit and for profit providers. The data is sensitive and there needs to be a stronger deterrence effect.

Therefore if there was to be inappropriate access to confidential patient records, the contracting between the Commonwealth and the successful provider of the Registry, in this case, Telstra Health, should be appropriately penalised to ensure the consequences are a deterrent. To ensure a smooth passage of the National Cancer Screening Registry Bill, PA would support a review of the quantum of the penalty for such a breach to ensure these penalties are appropriate and of a significant amount to ensure they are a deterrent.

***Recommendation 5:***

***PA supports a review of the fine for offences related to the unauthorised access of the Registry to ensure they are an appropriate deterrent related to the confidential nature of the Registry.***

***Length of contract***

Pathology Australia believes and has previously argued that the National Cancer Screening Registry should be scalable and sustainable for some years into the future. PA believes in the future proofing of the register, the principle of being able to add further Cancer registries data over time, and thus believes the terms of the contract are reasonable and for an appropriate length of time. Options should be a key component of the contracting between the commonwealth and the successful tenderer, Telstra, with continued contracting based on clear and agreed performance based criteria. As such, PA is supportive of the current length of contract and options for extension, with appropriate evaluation against performance to be part of the contracting and subsequent decisions for extension.

***Recommendation 6:***

***PA supports a long term approach to the contracting of the National Cancer Screening Registry and supports the use of a fixed term, with extension options, for the successful provider. This will enable the sustainability of the register into the future.***

**Concluding Comments**

Pathology Australia on behalf of all private Pathology providers in Australia supports the passage of the National Cancer Screening Register Bill 2016 and National Cancer Screening Register (Consequential and Transitional Provisions) Bill 2016. We believe there should be no delay to the implementation of the National Cervical Screening Program post May 2017. An essential component of the National Cervical Screening Program is the National Cancer Screening Register. We believe this legislation puts in place the necessary patient privacy and confidentiality mechanisms that are seen in other parts of the public – private partnership that Australia's healthcare system is built on.



# Pathology

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