



Public Pathology
AUSTRALIA



Submission to Senate Inquiry

National Cancer Screening Register

Putting **patients** first

Executive Summary

Public Pathology Australia makes the following submission to the Senate Community Affairs Legislation Committee in relation to the National Cancer Screening Register Bill 2016 and National Cancer Screening Register (Consequential and Transitional Provisions) Bill 2016.

Public Pathology notes there are no publically available terms of reference.

Public Pathology Australia's submission focuses on:

- Cancer registries and the need for a national approach;
- Registry providers;
- Privacy; and the
- Future application of data.

Public Pathology Australia makes the following recommendations:

- There needs to be a National Cancer Registry;
- There should be are no undue delays in the establishment of the Registry;
- State/Territory based registries must be maintained until a national Registry is fully functional;
- There should be transparency around the processes that were undertaken as part of the Registry tender;
- Additional safeguards should be put in place for the national Registry, including explicit requirements for the Registry operator to work within specific screening standards and more appropriate penalties for breaching privacy; and
- The Australian Government must retain the ability to access and analyse screening data in the national interest.

There is a need for a National Cancer Registry
with significant patient data privacy safeguards

Background

Public Pathology Australia

Public Pathology Australia is the national peak body for public pathology in Australia.

Pathology is the medical specialty that focuses on determining the cause and nature of diseases. By examining and testing body tissues (e.g. pap smears, biopsies) and fluids (e.g. blood, urine), pathology helps doctors diagnose and treat patients correctly. 70 per cent of all medical diagnoses and 100 per cent of all cancer diagnoses require pathology.¹

Public pathology represents a core part of Australia's public hospital and health care services. Unlike other pathology providers, public pathology providers operate for the benefit of patients and the public health system.

Public Pathology Australia members are the major government owned and operated pathology services in each State and Territory in Australia. They provide the vast majority of pathology services in Australia's public hospitals, service a number of private hospitals, and operate community based collection services for patients upon referral from GPs and Specialists.

In addition to diagnostic services, our members conduct research and teaching in the areas of new and existing diseases, tests and treatments, and collaborate closely with colleagues in all areas of patient care, with many pathologists also performing clinical roles. Their laboratory testing and medical consultation services play a crucial role in timely clinical diagnosis, in monitoring therapy and in prevention of disease in individuals and the community.

Public Pathology Australia members test cervical specimens and report to cervical screening registries under the National Cervical Screening Program (NCSP). Our members do not operate cancer registries. The high quality, responsive testing by public pathology providers are a critical part of the NCSP. Public pathology providers also undertake the vast majority of the more complex testing that is required when an abnormality is found on a screening test. Since the introduction of the NCSP in 1991, the incidence, morbidity and mortality from cervical cancer in Australia has reduced and is low by international standards.²

National Cervical Screening Program

From 1 May 2017, the National Cervical Screening Program (NCSP) will change from the two yearly Pap test to five yearly Human Papillomavirus (HPV) test with partial genotyping and reflex Liquid Based Cytology (LBC) for Australian women aged between 25 and 74 years. Public Pathology Australia fully supports this change and has been involved in transitional planning arrangements with the Australian Department of Health and our members.

The NCSP is currently supported by eight separate state and territory cervical screening registers across Australia. These registers collect, store and report cancer screening information and are an important part of the NCSP. As part of the forthcoming changes to the NCSP, state and territory governments may opt in to a national Registry.

¹ Bayram C, Britt H, Miller G, Valenti L 2009. Evidence-practice gap in GP pathology test ordering: a comparison of BEACH pathology data and recommended testing

² AIHW 2016. Cervical screening in Australia 2013–2014. Cancer series no. 97. Cat. no. CAN 95. Canberra: AIHW.

Submission

Cancer Registries

Public Pathology Australia strongly supports one National Cancer Screening Register (Registry). A single national Registry would assist clinicians with decision making as it would enable easy access to the medical history for all patients in the program. This addresses the issues that arise when participants are transient. It would also streamline the process for follow ups and reminders which are currently sent to patients from pathology laboratories and/or registries. A national Registry is also a potentially more cost effective way of managing the digital health infrastructure for population based screening programs into the future.

It is at the discretion of the states and territories to opt in to the Registry. It is important that our members receive confirmation as soon as possible as to which states and territories have opted in to the Registry so that our members can make the appropriate changes to their laboratory information systems.

There should be no delays to the 1 May 2017 commencement for the NSCP changes. The Australian Government has already circulated information about the change to laboratories, patients and health practitioners. Considerable planning for the May 2017 change has already taken place. The NSCP changes are significant and any delay would cause confusion and undermine the effectiveness of the program. Ideally, the national Registry should be ready prior to 1 May 2017. It is critical for continuity of the NSCP and the health of patients, that state and territory based registries be maintained until the national Registry is fully operational.

Registry Providers

There are established, reputable government and not for profit providers operating cancer registries in Australia. The providers of these registries have a strong track record, the necessary infrastructure and processes to properly house and protect patient data.

Public Pathology Australia has not viewed the tender specifications, nor the terms of the contract for the Registry. It is essential that due process was followed in terms of probity and the tender evaluation. Public Pathology Australia is not in a position to comment on whether this was done and trusts that this will be reviewed in this Senate Inquiry. Transparency of the tender process would bolster confidence in the selection of the Registry operator.

Privacy

Privacy of patient data is paramount in the provision of health care and population based screening programs. Any operator of a cancer registry should have clear, strong safeguards in place to protect patient information. Our members have not yet been informed about the safeguards the operator proposes to put in place for Registry data. As the selected operator is entering the healthcare data business which considers commercial applications for the use of health data, public perception may influence the need to have high visibility of those safeguards.

Any breaches of patient data should be penalised in a manner consistent with the seriousness of the breach, and in a similar way to what currently exists for patient information. Penalties may range from significant fines to criminal sanctions. This should be amended in the Bill.

Future applications

Enhancing the Registry to receive other screening data (e.g. breast cancer data) is a cost effective use of resources. This should be supported only when the infrastructure and processes for the Registry are robust and well established.

Public Pathology Australia understands that operation of the Registry will be informed by the Australian Government and the NSCP governance structures. To protect the patients from potential breaches of privacy and to ensure that pathology accreditation is not jeopardised, it should be explicitly mandated that the Registry operator adhere to the relevant Australian Government approved guidelines. For example, the Registry operator should only require additional or different information about a patient and patient's test results from a pathology provider if these are required by the National Pathology Accreditation Advisory Council (NPAAC) and/or the Cancer Council standards.

Patient data has significant value in informing health policy and resourcing decisions. Registries should provide a strong data warehouse for epidemiological research that might allow future better targeted treatment strategies. There must be appropriate provisions to ensure the Australian Government continues to have access to the NCSP data, and that this does not remain the property of Registry operator. This would provide an additional protection to patients, and ensure that the government is not beholden to the Registry operator for data and analysis that would be in the national interest.

Recommendations

Public Pathology Australia makes the following recommendations:

- There needs to be a National Cancer Registry;
- There should be no undue delays in the establishment of the Registry;
- State/Territory based registries must be maintained until a national Registry is fully functional;
- There should be transparency around the processes that were undertaken as part of the Registry tender;
- Additional safeguards should be put in place for the national Registry, including explicit requirements for the Registry operator to work within specific screening standards and more appropriate penalties for breaching privacy; and
- The Australian Government must retain the ability to access and analyse screening data in the national interest.



Jenny Sikorski
Chief Executive Officer
Public Pathology Australia

22 September 2016

