



Submission to the

**Senate Standing Committee on Community Affairs
*Inquiry into the National Cancer Screening Register Bill 2016 and the
National Cancer Screening Register (Consequential and Transitional
Provisions) Bill 2016***

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Introduction

The Australian Healthcare and Hospitals Association (AHHA) welcomes the opportunity to provide a submission as part of the Senate Standing Committee on Community Affairs' inquiry into the *National Cancer Screening Register Bill 2016* and the *National Cancer Screening Register (Consequential and Transitional Provisions) Bill 2016*.

AHHA is Australia's national peak body for public and not-for-profit hospitals and health care providers. Our membership includes state health departments, Local Hospital Networks and public hospitals, community health services, Primary Health Networks and primary healthcare providers, aged care providers, universities, individual health professionals and academics. As such, we are uniquely placed to be an independent, national voice for universal high quality healthcare to benefit the whole community.

Establishment of the National Cancer Screening Register

The *National Cancer Screening Register Bill 2016* and the *National Cancer Screening Register (Consequential and Transitional Provisions) Bill 2016*, currently before the Commonwealth House of Representatives, will establish the National Cancer Screening Register for the National Cervical Screening Program and the National Bowel Cancer Screening Program, through migrating existing bowel cancer screening and state and territory cervical-screening data from nine existing registers to the new national register.^{1,2}

On 26 May 2016, the Commonwealth Department of Health announced that, following a detailed request for tender process that commenced on 10 August 2015, a contract was signed on 4 May 2016 awarding a \$220 million five year contract to establish and operate the new National Cancer Screening Register to Telstra Health, with an option for a 10 year extension.^{3,4}

First announced in the 2015–16 Commonwealth Budget, the Government failed to pass the necessary legislation in the 44th Parliament before its double dissolution on 9 May 2016. The result being the previous bills lapsed and the current bills' introduction in the 45th Parliament on 31 August 2016.

While AHHA welcomes investment in and development of the National Cancer Screening Register as an important national health data resource to contribute to better health outcomes and to support research and health policy development, it is imperative that data governance and security arrangements are in place and managed very carefully.

The new national register will hold personal data such as an individual's name, address, contact details, date of the birth, gender, Medicare item number, Medicare claims information, preferred general practitioner and other health providers along with private and intimate health data.

The Department of Health has stated its Information Technology and Population Health and Sport Divisions will now work with Telstra Health to implement the register with significant collaboration with the Department of Human Services and the state and territory governments to transition nine separate cancer registers into a single National Cancer Screening Register. The register is expected to

¹ http://www.aph.gov.au/Parliamentary_Business/Bills_Legislation/Bills_Search_Results/Result?bId=r5700

² http://www.aph.gov.au/Parliamentary_Business/Bills_Legislation/Bills_Search_Results/Result?bId=r5699

³ <http://www.health.gov.au/internet/main/publishing.nsf/Content/mr-yr16-dept-dept002.htm>

⁴ <http://www.abc.net.au/news/2016-05-26/telstra-wins-contract-for-new-national-cancer-screening-register/7449782>

be operational to align with the commencement of the renewed National Cervical Screening Program on 1 May 2017.

Transparency and due diligence

With regards to the awarding of a tender of this magnitude dealing with sensitive, nationally important data over a period of possibly up to 15 years, it is important that the Commonwealth Government is transparent with the public, the health sector and affected stakeholders on its decision making process, its contractual arrangements with Telstra Health, its implementation planning, its criteria for success, and the value propositions for patients, clinicians, researchers and policy makers.

Unfortunately, the tender and contractual arrangements with Telstra Health are not publicly available making it difficult to understand how Telstra Health will lead this work. Because they do not have established health registries, it is difficult to assess the expertise Telstra Health will bring to this work compared with other established operators of health registries and statistical collections. However, we note recent reports that Telstra Health's subsidiary, Emerging Systems, will build the new national register, has experience in handling sensitive medical records and built a data register on behalf of St Vincent's Hospital.⁵

Key concerns

AHHA supports the government's policy intent of strengthening Australia's cancer-screening programs and establishing the National Cancer Screening Register. However, a number of concerns need to be addressed.

For profit vs not-for-profit provider

The issue of Telstra Health being a for-profit provider is not a critical definer as to their capacity to run the register as long as there are appropriate contractual arrangements with the Commonwealth that ensure data governance and security arrangements are in place and managed very carefully; that there will be appropriate and complete separation of Telstra Health's other commercial interests and activities from the new national register; and that de-identified data will be publicly reported and made available for researchers, clinicians and policymakers without additional commercialisation.

National Cancer Screening Register costs or savings

The Commonwealth has not provided details on the expected costs or savings that will result from the move away from the current eight state and territory cervical cancer screening registers and the national bowel cancer screening register. Public disclosure of this information will assist in determining if Australians will receive value for money in the \$220 million, five year contract with Telstra Health.

Data

A key concern deserving substantial consideration relates to data as outlined below.

Data exclusions

The Commonwealth has not provided a rationale on why the current state and territory based breast cancer screening registers are excluded from the Telstra Health contract.

⁵ <https://www.pulseitmagazine.com.au/australian-ehealth/3351-quick-fire-senate-inquiry-into-national-cancer-screening-register>

Data strategy

The Commonwealth has not indicated how its proposed national register aligns with Cancer Australia's 2008 *A National Cancer Data Strategy for Australia*⁶ that outlined strategies and activities to improve cancer data development, analysis and use.

Data governance arrangements

The Commonwealth must be sure that data governance arrangements are in place not just via legislation but in the architecture of the registry, the technical infrastructure at Telstra Health and the expertise of the individuals running the cancer registry. This will ensure Australians can have confidence that data are going to be governed properly and held securely.

The Commonwealth must ensure that Telstra, a proponent of big and open data, does not allow its commercial interests to use personal data for uses beyond what they were originally collected nor to push the limits of privacy and data protection laws.

Offence and penalties

The bills seek to create an offence arising from the unauthorised collection, use or disclosure of personal information contained in the register. However, the size of the penalty in relation to unauthorised collection, use or disclosure is only \$21,600.

While the penalties for breaching the bills' privacy provisions, inadvertent or not, are enough to deter small, not-for-profit organisations, they are not enough to deter a large, for-profit entity such as Telstra Health. The automatic penalties must be great enough that any risk-management strategies will ensure the organisation and its managers always have consumer privacy as a key concern. In comparison, the enabling legislation for the Australian Institute of Health and Welfare (AIHW) provides for prison terms for anyone who breaches matters that are defined in the legislation.⁷

Legislation and the contract between the Commonwealth and Telstra Health should prescribe tough financial penalties that have automatic effect after any unauthorised data release. Furthermore, the proposed bills should be consistent with similar prison-term provisions to those found within the AIHW's enabling legislation.

Cybersecurity

Australians often do not know when their personal cybersecurity has actually been breached because companies are under no obligation to inform the victims that this has occurred. Commonwealth (and some state and territory) privacy legislation⁸ provides some protection for individuals' personal information, and in particular sensitive and health-related information.

In 2008, the Australian Law Reform Commission recommended the *Privacy Act 1988* be amended to impose a mandatory obligation to notify the Privacy Commissioner and affected individuals in the event of a data breach that could give rise to a real risk of serious harm to affected individuals.⁹ The Office of the Australian Information Commissioner developed a guide for agencies and organisations

⁶ https://canceraustralia.gov.au/sites/default/files/publications/ncds_final_web1_504af02093a68.pdf

⁷ <https://www.legislation.gov.au/Details/C2012C00033>

⁸ <https://www.oaic.gov.au/privacy-law/privacy-act/health-and-medical-research>

⁹ <http://www.alrc.gov.au/publications/51.%20Data%20Breach%20Notification/alrc%E2%80%99s-view>

when responding to a data breach, though compliance with the guide is not required under the Privacy Act.¹⁰

The Commonwealth Attorney-General's Department undertook public consultation on its draft mandatory data breach notification bill¹¹ and attempted twice to pass the *Privacy Amendment (Privacy Alert) Bill 2014* in the 44th Parliament. However, the bill first lapsed due to the prorogation of the first session of the 44th Parliament on 17 April 2016 and subsequently lapsed due to the double dissolution of the 44th Parliament on 9 May 2016.¹² As a result, agencies and organisation continue to report to the Privacy Commissioner on breaches on a voluntary basis.

Legislation and the contract between the Commonwealth and Telstra Health should prescribe mandatory data breach notification to require notification to both the Privacy Commissioner and affected individuals as soon as practicable when there is clear evidence personal information has been compromised in relation to the National Cancer Screening Register. Equally, legislation and the contract should stipulate notification requirements when there is a potential breach, for example when information technology systems are hacked or there is evidence of an information technology failure that allows people to see identifiable information. It is critical that strong legislative and contractual frameworks are in place to protect individuals' privacy in the event of both a clear data breach and potential breach.

Linkages with research, clinicians and policymakers

It is important that the data to be housed in the National Cancer Screening Register are made appropriately available for clinical research and also to understand the incidence of cancer in our society, the way we fund the care of people with cancer, what it means in terms of the funding and organisation of our health system. This will allow researchers, clinicians and policymakers to ensure health policy is evidence-informed.

Exemplifying the value of cancer screening data in shaping clinical practice and informing health system policy is the work published by the Victorian Cytology Service and the Australian Institute of Health and Welfare (AIHW) regarding the early effect of the HPV vaccination program in Victoria.^{13,14}

Without the clinical perspectives and the opportunity to conduct data linkage with other health data sets made possible through collaborative efforts such as this, the value of the National Cancer Register will not be fully realised. It is not yet clear if Telstra Health will be required to provide the cancer data they will hold to agencies such as Cancer Australia and the AIHW, in particular, who have important national roles in the collection, management and reporting of cancer statistics. It is important the Commonwealth clearly outlines who will be responsible for analysing these data, how often will this be done, whether the reports be made public and who will ensure the validity of the results.

Contract extension, expiration and termination

The Commonwealth should explicitly outline how it intends to determine whether its five year contract with Telstra Health should be extended, and what data arrangements are in place at the expiration or termination of the contract with Telstra Health.

¹⁰ <https://www.oaic.gov.au/agencies-and-organisations/guides/data-breach-notification-a-guide-to-handling-personal-information-security-breaches>

¹¹ <https://www.ag.gov.au/consultations/pages/serious-data-breach-notification.aspx>

¹² <http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22legislation%2Fbillhome%2Fs958%22>

¹³ <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129545152>

¹⁴ [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)60551-5/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60551-5/fulltext)

The Department of Health's website states that: the Commonwealth is the custodian of the data stored in the Register; Telstra Health owns the IP associated with the Register software required to operate the Register; and at the end of the contract, the Commonwealth will be able to continue to licence the software, including making it available to a new Register Operator.¹⁵

It is not clear what will happen when the Telstra Health contract expires in five years' time and the process by which a potential 10 year extension may be offered. Due diligence suggests a competitive process with other potential providers should be undertaken.

Conclusion

While AHHA supports the government's policy intent of strengthening Australia's cancer-screening programs and establishing the National Cancer Screening Register, a number of concerns need to be addressed.

The Commonwealth must be forthcoming on the anticipated costs or savings associated with moving away from the nine existing registers to the new National Cancer Screening Register, and its outsourcing to a for-profit provider.

The Commonwealth must also address a number of key concerns related to data, which include:

- the rationale for the exclusion of the current state and territory based breast cancer screening registers;
- how the new national register fits in with Cancer Australia's 2008 national cancer data strategy;
- the proposed data governance arrangements essential for instilling confidence that data are going to be governed properly and held securely;
- the need for appropriate penalties for data and security breaches;
- the need for mandatory data breach notification, for both clear and potential data breaches in relation to the register, to the Privacy Commissioner and to affected Australians as soon as practicable; and
- the need for data to be housed in the National Cancer Screening Register made appropriately available to researchers, clinicians and policymakers to ensure health policy is evidence-informed.

The Commonwealth should explicitly outline how it intends to determine whether its five year contract with Telstra Health should be extended, and what data transfer arrangements are in place at the expiration or termination of the contract with Telstra Health.

AHHA welcomes the opportunity to provide this submission to the Senate Community Affairs Legislation Committee and looks forward to the Committee's report.

AHHA advocates for health reforms that maintain and improve health outcomes, and support equity, accessibility and sustainability of the broader Australian health system to the benefit of the whole community.

¹⁵ <http://www.health.gov.au/internet/main/publishing.nsf/Content/National-Cancer-Screening-Register>