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"We take it personally"

Committee Secretary
Senate Standing Committees on Community Affairs
P.O. Box 6100
Parliament House
Canberra ACT 2600

Re: National Cancer Screening Register Bill 2016 and National Cancer Screening Register (Consequential and Transitional Provisions) Bill 2016.

Introduction to the Author of this Submission

Professor Annabelle Farnsworth

MBBS(Hons), FRCPA, FIAC, DipCytopath(RCPA), RANZCOG (Hon), Adjunct Professor School of Medicine University of Notre Dame, Medical Director Douglass Hanly Moir Pathology, Director GynaePath (Specialist Gynaecological Pathologists), President Australian Society for Colposcopy and Cervical Pathology (ASCCP), Member Executive Council International Society of Cytology.

Douglass Hanly Moir Pathology provides that largest cervical screening service in Australia. In addition to routine cervical screening we undertake extensive clinical consultation with referring practitioners, provide extensive educational material and conduct seminars in the area of cervical screening. We deliver training and continuing education programs for scientists, pathologists and registrars. The department runs and participates in many research projects and has published numerous peer reviewed scientific papers.

As the Director of the department I have been an important contributor in developing National Quality Standards in cervical screening and am a member of the Technical Advisory Group in Gynaecological Cytology for the National Pathology Accreditation Advisory Committee (NPAAC). I am also the current President of the Australian Society of Colposcopy and Cervical Pathology.

The Douglass Hanly Moir Laboratory processes many thousands of patients' samples every day. The laboratory has an enviable record of outstanding clinical service, research and quality. We are part of a larger publically listed company, Sonic Healthcare which employs 14,000 people across Australia. In order to provide appropriate medical care we must have access to patient's private health information. We have strict policies and a deep understanding of our duty surrounding this aspect of our work.



Summary

All parties (Government, Opposition, Greens and Independents) agree that Australia needs an efficient and modern National Cancer Screening Register (NCSR).

The contract for this critical piece of infrastructure has been awarded to Telstra Health after an exhaustive public tender process. It does not represent wholesale privatisation of the healthcare system. It follows independent evaluation of competitive bids and a decision designed to provide the best overall value for Australian taxpayers.

Suggestions that 'for profit' organisations should not be allowed to access sensitive personal data fail to recognise the current operation of the Australian healthcare system in which multiple 'for profit' organisations provide high quality critical services efficiently and with due respect to the ethical and legislative requirements around privacy and appropriate use of this data.

Most importantly any delay to the passage of this legislation will have important consequences for cervical screening in Australia which is currently in transition to a new program reliant on the services to be provided by the NCSR.

Submission

As the director of Australia's largest cervical screening service I would like to appeal to the Standing Committee on Community Affairs to separate the politics surrounding the objections to the passage of the National Cancer Screening Register Bill 2016 and National Cancer Screening Register (Consequential and Transitional Provisions) Bill 2016 and consider the consequences for Australia's cancer screening services, in particular the cervical screening service.

The National Cancer Screening Register (NCSR) forms an integral component of the Renewed Cervical Screening Program due to commence on May 1st 2017. This change will see the current Pap smear offered to women every 2 years replaced by a very much less labour intensive HPV test offered every 5 years.

Australia will be one of the first countries in the world to make this significant change.

The transition to the new program has already begun. The scientists trained to report Pap smears are necessarily moving to alternate careers. It needs to be clearly understood that the remaining workforce *will not* have the capacity to support the current program beyond the proposed start date of the Renewal.

Any delay to this implementation places the health of Australian women at risk.



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Concerns voiced by the Opposition's Shadow Health Minister MP Catherine King and supported by the Greens and some Independents focus not on the value of a NCSR, as all parties agree on this, but rather on the concern that private and sensitive information on an individual's medical status will be made available to a private, 'for profit' organisation, Telstra Health.

The reality is that the majority of our health system –including small GP surgeries, larger medical centres, private hospitals, radiology and pathology practices- is comprised of 'for profit' organisations, all of which hold sensitive and personal data that is critical to the practice of good medicine.

All these 'for profit' entities operate under strict privacy rules and I am certain the legal and contractual obligations inherent in the contract for the NCSR provide for the most stringent protections. The only assertion made by the Opposition that I can find any justification in is a review (and possible increase) of the penalties for offences dealing with unauthorised use, or disclosure of personal information contained in the register.

The tender process for the NCSR was lengthy and thorough, entirely appropriate for a major and long term investment of public funds in advanced technological infrastructure that must consolidate Australia's current inefficient and fragmented cancer screening databases. The requirements are clear - we need a cost effective, modern solution that provides secure and efficient data collection and storage together with capacity for future expansion and ease of use for all stakeholders. It is not surprising that a company with the capabilities of Telstra Health was successful.

The inference that the awarding of the contract was secretive or rushed is unjustified. This was a public tender process conducted over several months and timed to coincide with the established implementation schedule required to meet the May 1st 2017 deadline of the Renewal of the cervical screening program. It would be more accurate to observe that the recent Federal Election had more to do with the delay in tabling the legislation than a deliberate attempt by the Health Minister to mislead Parliament.

While it is true that Telstra Health has not previously run a cancer register they have gone to great lengths to engage clinical staff with the appropriate expertise and experience. Indeed the Director of the Cervical Cancer Screening Register for Telstra Health, Professor Dorota Gertig, previously held the position of Medical Director at the Victorian Cytology Register, recognised by the Opposition as an excellent service. Many other staff have been sourced from this register and others around the country giving a broad register experience base to add to their technological expertise.

The Opposition rightly points out that this is a sizeable contract in monetary terms with an initial five year contract period plus an additional option for a further ten years. I find that this is reasonable



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when consideration is given to the significant investment of time, expertise and money that will be required to first establish and then maintain such a register. As described above by recruiting a well-credentialed team Telstra Health has already committed significant resources to this project, actions that demonstrate a long term commitment to the register rather than a plan for short term profit.

The fields of cancer screening and vaccination are becoming more closely linked. Nowhere is this more evident than in cervical cancer screening where the HPV vaccine has been the catalyst for the upcoming changes to the screening program. The NCSR will need a clear pathway through current legislation in order to efficiently migrate critical data into its database. This action is facilitated by the National Cancer Screening Register (Consequential and Transitional Provisions) Bill 2016 as is the appropriate expansion of the information collected by the register to meet future advances in scientific and technological knowledge. I also support the measures contained in this document.

Recommendations

1. That the Senate Standing Committee on Community Affairs dealing with this inquiry return a recommendation to support the National Cancer Screening Register Bill 2016 and National Cancer Screening Register (Consequential and Transitional Provisions) Bill 2016 thus allowing the process of the Renewal of the cervical screening program to meet the May 1st deadline.
2. That the politically motivated amendments proposed by the Opposition which allow only Government operated or 'not for profit' entities to operate the NCSR are not included in this legislation.
3. That the appointment of the successful tenderer Telstra Health be upheld.
4. That the Senate Standing Committee on Community Affairs dealing with this inquiry review the penalty assigned to the offence created by the bill for unauthorised collection, use or disclosure of personal information contained in the register. The Committee should be comfortable that the penalty is reflective of the seriousness of the offence.

Further Information

In support of this submission I am happy to appear at the public hearing scheduled for September 29th 2016. Please note that I am available before 1pm only due to commitments concerned with the changes to the cervical screening program.