



School of Public Health and Preventive Medicine
Faculty of Medicine, Nursing and Health Sciences

21 September 2016

Committee Secretary
Senate Standing Committee on Community Affairs
PO Box 601000
Parliament House
Canberra ACT 2600

Dear Secretary

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

I understand that both of these bills have been referred to the Senate Community Affairs Legislation Committee for inquiry and report. I would therefore like to make the following comments on behalf of the School of Public Health and Preventive Medicine of the Faculty of Medicine, Nursing and Health Sciences at Monash University.

- We have worked with Telstra at various stage in the development of their application to manage the National Cancer Screening Registry. During the course of this work, we provided Telstra with some advice based on our experience in the management of a large number of clinical registries.
- We have been very supportive of the plan to develop a National Screening Registry for Cervical and Bowl Cancer. Screening is one of the most effect ways of reducing the incidence of cancer in our community. At a time when treatment options for many cancers are limited and increasingly expensive, the role of screening has an increasingly important role to play.
- We consider it very important that a national system is developed where definitions and procedures are identical, regardless of which state the data is collected from. This is not only important in tracking individuals who might move from one state to another, but will also prove an invaluable resource when it comes to improving the uptake of screening, increasing its accuracy and ultimately understanding the impact of these registries in reducing the incidence and mortality from bowel or cervical cancer. Further, carefully collected and epidemiologically sound data will be essential to inform future policy initiatives in this area.
- We believe that the development of a national program of the type envisioned is well beyond the capacity of any academic institution. It requires a nation-wide infrastructure linking general practitioners, hospital pathology laboratories and innumerable public and private specialists with links to large segments of the community. The successful development of this infrastructure will require a very substantial organisation with a national infrastructure and a strong background in the development of innovative solutions to secure data capture and data transfer. From our interactions over many months, we have observed that Telstra has

the capability and capacity to undertake such a scheme, having approached this issue in the understanding that absolute priority must be given to patient privacy and individual confidentiality.

- Security of data: we understand that the national screening registry will be audited regularly by an independent government certified auditor. We note further that the government has a variety of mandatory privacy and security requirements and will follow an accreditation process similar to that used by the MyHealth record.

From our review of the process, we believe that there is appropriate privacy and security controls and are reassured that these will be under continuous scrutiny.

In summary, while we fully agree that privacy and confidentiality must be paramount, we are very supportive of the award of the tender to Telstra for the reasons highlighted above and look forward to the substantial improvement in public health that will ensue from the successful implementation of this scheme.

We would be more than happy to appear before the Committee at your request.

Yours sincerely

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