SUBMISSION TO SENATE COMMUNITY AFFAIRS COMMITTEE

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

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I am making this submission as an individual with considerable experience and expertise in the development, implementation and evaluation of health policy, including several years (1996-1999) as Manager for Policy, Planning and Resource Management at the NSW Cancer Council. This submission does not represent the views of the Menzies Centre for Health Policy or the University of Sydney.

In assessing the impact of this legislation, there are a number of major issues for the Committee to consider:

1. This legislation comes after the Government has already contracted with Telstra Health to implement the National Cancer Screening Registers for cervical cancer and bowel cancer. The contract has not been made public, so it is not possible to know how (or even if) the contract and the proposed functioning and outcomes for the Registers, as outlined in the Explanatory Memoranda, align. We do not know the basis on which Telstra Health was awarded the contract over other applicants and who those applicants were; we do know that Telstra Health has no current expertise in this area.

2. The Government has provided no rationale or information about why the current State and Territory based breast cancer screening registers are not included in this initiative, and about the costs or savings that will result from the privatisation of the eight State and Territory cervical cancer screening registers and the national bowel cancer screening register. The Telstra Health contract is $220 million / 5 years: where does this funding come from?

3. We know that the Department of Human Services was not an applicant to run the new National Cancer Screening Registers (we can only assume that they were not encouraged to do so) but why was this work not centralised in existing Commonwealth agencies such as the Australian Institute of Health and Welfare (AIHW) or Cancer Australia which are already heavily involved in this work and have much of the needed expertise? For example, the AIHW currently compiles the Australian Cancer Database from data provided by the various cancer registers around Australia.

4. There is no indication that this effort takes any note of the recommendations made in *A National Cancer Data Strategy for Australia* which was produced by Cancer Australia, following considerable public consultation, in 2008.[1] This report (admittedly now somewhat dated, but still valuable) makes a cogent case for the value of the range of cancer screening and clinical registers and cancer bio-specimen registers in Australia to policymakers, researchers, clinicians, patients and the community at large. These are precious resources to

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[1] https://canceraustralia.gov.au/sites/default/files/publications/ncds_final_web1_504af02093a68.pdf

inform prevention, screening, treatment, guidelines, population targeting and service needs and must not be squandered. It appears that the current Government strategy is either to ensure that there is no such National Cancer Data Strategy or to surreptitiously outsource all of this to the private sector. There has been no public discussion of this so we are left to intuit Government's long-term intent.

5. What happens when the Telstra Health contract expires in five years' time – will it automatically be renewed, will it be up for competitive bids? How will this 'contestability' affect the continuity, ongoing resources and work needed for these registers?

6. The scope of the work which this legislation will allow Telstra Health to undertake is quite substantial, and gives cause for concern that this has not received sufficient attention from all the stakeholders involved. This is about much more that sending reminders to Australians about cervical cancer or bowel cancer screening. Telstra Health will have the ability to access data from the Australian Immunisation Register, from the AIHW and from Medicare claims and the Registers will be 'integrated' with GPs, specialists and pathology laboratories. Will the Australian population be comfortable with the fact that a for-profit business knows whether they have been vaccinated against HPV or tested for a range of human papilloma viruses, whether they have had a full or partial hysterectomy, if they are at risk of bowel cancer because of familial polyposis, and when they last had a colonoscopy and what the pathology findings were? Will GPs, specialists and diagnostic labs be happy that Telstra Health (or some other business) can, at least potentially, scrutinise their diagnoses and treatment? While there are acknowledged efficiencies in such linked-up data, this must not evade the current stringent ethical and privacy requirements for such efforts.

7. It is not clear if Telstra Health is required to provide cancer data they will hold to the AIHW. Who will now be responsible for analysing these data, how often will this be done, will the reports be made public, and who will ensure the validity of the results? This is particularly important as such data are used to inform resources, targeting and policy reforms – and also to assess the efficiency of operations of the registers. It is also not clear how academic and clinical researchers will access the data that Telstra Health will hold. The Department of Health website states that the Department "is currently developing a data access and release policy for the Registers to provide researchers with guidance for access to (de-identified) data". If Telstra Health starts to integrate cancer information with their own databases, then the possibility exists that they will declare the cancer data they hold as 'commercial-in-confidence'. This possibility has clearly been considered as the legislation states that the Minister has the power to decide if information is commercial-in-confidence.

8. Telstra Health is a for-profit business entity looking to establish itself in this space and others. What are the protections to ensure that the names, contact details and medical information of people on the National Cancer Screening Registers are not used by Telstra Health in support of other business activities? While the most egregious such cases will presumably be prevented by privacy provisions, what is the situation if Telstra Health is pushing prevention or treatment options for conditions related to cervical cancer or bowel cancer?

9. There are provisions in the legislation for people to opt out of the new National Cancer Screening Registers, but it is not clear how this information will be conveyed. As it stands, the current low rates of screening are unlikely to be improved by a reminder from Telstra Health without considerable work to build community trust. This is especially important as under-screened groups include CALD and Indigenous communities.

10. It is not clear how individuals will access their data in the National Cancer Screening Registers – whether this will be done directly or via My Health Record. If it is the latter, does this mean that Telstra Health will also have the ability to view these patient records?

I am not an expert on privacy issues and so feel unable to comment on the important privacy issues that this legislation raises, except to say that the proposed provisions to protect privacy and prevent the release of protected information seem inadequate, are not preventive but come into play after the fact, and have loopholes (for example, there is an exception for the release of protected information if this is done "in good faith").

I believe that it is important, for the protection of both public trust and the valuable resource that the ongoing collection and analyses of cancer data provides, that the range of issues raised by this legislation are fully understood by all stakeholders, especially the Australian public, and addressed. Decisions made now will have impacts into the future.