

22 September 2016

The Senate Standing Committees on Community Affairs

NATIONAL CANCER SCREENING REGISTER BILL 2016 AND NATIONAL CANCER SCREENING REGISTER (CONSEQUENTIAL AND TRANSITIONAL PROVISIONS) BILL 2016

Our Organisation

The Menzies School of Health Research (Menzies) is Australia's only medical research institute dedicated to improving Aboriginal and Torres Strait Islander health and wellbeing. We have a 30-year history of scientific discovery and public health achievement. Menzies was established in 1985 as a body corporate of the Northern Territory Government under the Menzies Act 1985. This Act was amended in 2004 to formalise the relationship with Charles Darwin University (CDU). Menzies is now a major partner of CDU and constitutes a school within the University's Institute of Advanced Studies.

We work to develop enduring solutions to problems that matter; the kind that when tackled, have the potential to make an immense difference to the quality of lives both here and abroad. For more than 30 years Menzies has been partnering with Aboriginal and Torres Strait Islander communities and disadvantaged populations across our region to improve health outcomes and reduce health inequity. Through a commitment to excellence in research, the development of evidence-based programs and the fostering of local capacity through training and employment, Menzies is tackling significant Aboriginal and Torres Strait Islander health issues, including cancer.

Menzies has a long history of work around Aboriginal and Torres Strait Islander cancer screening. We are currently involved in two major projects. In one, we are working closely with the Australian Government Department of Health to carry out a National Indigenous Bowel Screening Project, to firstly, consult with Aboriginal and Torres Strait Islander people and those providing health care and screening services, and secondly, pilot an alternative pathway to the National Bowel Cancer Screening Program. We are also leading the National Indigenous Cervical Screening Project (NICSP), in partnership with Queensland Cancer Council, NSW Cancer Council, Victorian Cervical Screening Service and the Australian National University. This research project aims to address a major deficiency in the current National Cervical Screening Program (NCSP): a failure to record and report on screening participation and other key performance indicators for Aboriginal and Torres Strait Islander women¹. This deficiency has resulted from the absence of an indigenous identifier on pathology report forms, which inform the Pap test registers². We have made numerous representations to the NCSP to improve this gap.

This Menzies-led project has addressed this deficit in current knowledge through linkage of several existing administrative datasets to assign Indigenous status to the Pap test register³. This has enabled us to report on Aboriginal and Torres Strait Islander participation and other key indicators for the first time in the 25 year history of the program^{4,5}. Our analysis in one jurisdiction (Queensland), has reported that two thirds of Indigenous women do not participate in cervical screening⁵. We are now conducting national analyses.

The Bill

The National Cancer Screening Register Bill 2016 and the National Cancer Screening Register (Consequential and Transitional Provisions) Bill 2016 (collectively referred to as the NCSR Bills) will establish the National Cancer Screening Register (the Register), authorise collection, use and disclosure of information for the purposes of the Register, authorise the migration of bowel cancer screening and state and territory cervical screening data to the Register and mandate reporting of screening information to the Register. This Bill engages the following rights: protection of privacy and reputation (Article 17 of the International Covenant on Civil and Political Rights (ICCPR)); and right to health (Article 12(1) of the International Covenant on Economic, Social and Cultural Rights (ICESCR)). In August 2016, Telstra Health was awarded the contract to develop and manage the Register.

While Menzies supports the establishment of a national cancer screening register, we have identified a number of issues of importance for consideration by the Senate committee:

1. The importance of robust screening programs that serve the whole population

Aboriginal and Torres Strait Islander participation in both the NCSP and NBCSP is estimated to be considerably lower than that of the rest of the Australian population. The National Indigenous Bowel Screening Project has identified numerous barriers to Aboriginal and Torres Strait Islander participation that arise from the nature of the Program and the extent to which it works, or doesn't work, for Aboriginal and Torres Strait Islander people – and is working with key stakeholders (including the Department of Health/ NBCSP) to find ways to address these barriers. Similar work needs to be carried out to look at the barriers for Aboriginal and Torres Strait Islander people in relation to the NICSP. The NCSP has been successful in reducing cervical cancer incidence and mortality by over 50% among Australian women². Unfortunately Aboriginal and Torres Strait Islander women have not achieved this same benefit as they are twice as likely to be diagnosed with cervical cancer and four times more likely to die from it². **Unless barriers to participation are addressed, there is not equity of access to these programs.**

2. Consultation and Engagement with Aboriginal and Torres Strait people

There is overwhelming evidence that the development of robust policy and programs will be strengthened by the involvement of those who will be affected by the proposed change. Despite our lengthy and active involvement in Aboriginal and Torres Strait Islander cervical cancer issues, we are aware of little activity to engage with Indigenous women and Indigenous communities. Such engagement is paramount to the success of the renewed NCSP for Indigenous women and the new national screening register, and requires a relationship built on trust and integrity and agreement to work on shared goals.

Recommendations:

- That as a matter of priority, the Department of Health identifies a transparent process for consultation with Aboriginal and Torres Strait Islander people and health care and screening providers about the renewal of the NCSP, including the new register.
- We suggest an Aboriginal and Torres Strait Islander Advisory committee be established to advise the Department of Health and Telstra Health about the NCSP and NBCSP for the longer term.

3. Ensuring the Register includes high quality data on Aboriginal and Torres Strait Islander identification

- a. As outlined above, the absence of an accurate Indigenous identifier has made monitoring of Aboriginal and Torres Strait Islander participation in screening programs extremely difficult. It is imperative that the new register can address this deficiency. In the absence of a more accurate Indigenous identifier, monitoring of Aboriginal and Torres Strait Islander people in screening programs will not be possible.
- b. Our efforts to engage and assist the NCSP Renewal over several years, to overcome the significant barriers to identifying Aboriginal and Torres Strait Islander women on the Pap test registers, have largely been unsuccessful.
- c. The development of the new Register provides a valuable opportunity to address a critical information deficit, and we are concerned that – without adequately informed advice - Telstra Health might miss this opportunity.
- d. The lack of consultation with Aboriginal and Torres Strait Islander people may engender distrust in the system, and may discourage people from identifying.
- e. Article 12 of the OCESC Covenant, recognises ‘the right of everyone to the enjoyment of the highest attainable standard of physical and mental health’. How will this be achieved if monitoring of Aboriginal and Torres Strait Islander people in screening programs is not possible?

Recommendations:

- The new national screening register should address the serious data deficiencies in collecting and reporting on Indigenous status and be guided by highly qualified and experienced people in this area.
- To ensure this, we would recommend consultation with Aboriginal and Torres Strait Islander stakeholders and those who have expertise in record-linkage and collection of Aboriginal and Torres Strait Islander status in administrative data.

4. Privacy

- a. The new register is designed to hold sensitive information about every Australian who is eligible for the cancer screening programs. Given reports of previous breaches to data security, what guarantees do the public have that the Register will be able to maintain privacy?
- b. This Bill engages the rights to protection of privacy and reputation (Article 17 of the International Covenant on Civil and Political Rights (ICCPR). Again, how can this be guaranteed?
- c. Any breach of privacy – or perceptions of the risk of privacy breaches - has the possibility of a further disincentive to Aboriginal and Torres Strait Islander people to participate in screening and to record their Indigenous status in health records.

Recommendations:

- We recommend that Telstra Health and the federal government implement mechanisms to ensure the highest level of security of data.

5. Reporting

- a. Good quality data are critical to underpin strategies to improve the health of populations. The new Register will require an accurate Indigenous identifier to enable ongoing reporting against the key cancer screening performance indicators for Indigenous Australians.

Recommendations:

- We recommend that the Register have provision for routine monitoring of Aboriginal and Torres Strait Islander peoples' participation in screening services, ensuring that the quality of Indigenous Identification and other data is of the highest possible quality. Only through routine monitoring can we evaluate the performance of health services to address cancer disparities for Aboriginal and Torres Strait Islander people.

In conclusion, Menzies School of Health Research supports a national cancer screening register. However in establishing this register there needs to be a demonstrated willingness to engage all relevant stakeholders, including Aboriginal and Torres Strait Islander people. The accurate identification and reporting of Indigenous status must be a priority if we are to monitor change and improve the health and well-being of Aboriginal and Torres Strait Islander people.

Yours sincerely

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References:

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