



Consumers Health
Forum OF Australia

SUBMISSION TO SENATE COMMUNITY AFFAIRS LEGISLATION
COMMITTEE

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

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Introduction

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers and those with an interest in health consumer affairs. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

Screening programmes play an important role in supporting the early detection and prevention of cancer which can reduce the burden of the disease in the community. CHF welcomed the announcement of the establishment of a single National Cancer Screening Register to replace the National Bowel Cancer Screening Program Register and the eight State and Territory registers which support the National Cervical Screening program. We think this measure is overdue as we need consistent national data on the screening programmes to see how they are tracking and to help prioritise areas for action to increase the uptake of the screening programmes. We believe that when the new National Register is fully operational it will help increase participation rates and the overall effectiveness of the screening programmes.

CHF does question the process involved here when the contract to implement the register has been awarded prior to the Bill coming forward.

Issues

One of the key issues for consumers whenever registers or similar data collection processes are discussed is concern around privacy and protection of personal information. They will need to be assured that their personal information is protected if they are to have confidence in the register and continue to participate fully in the screening programmes.

The Bill allows the Register to collect individuals' key personal information including information which could identify them and about the results of their screening tests. For the register to be effective it also has to be able to share that information with appropriate providers and there need to be stringent safeguards around how that data is shared.

The Bill sets out in some detail the circumstances where collecting, recording, using or disclosing protected information is authorised. These are quite limited and are designed to ensure the personal information is collected and/or disclosed from the register only where it is associated with the purpose of the Register. Provided this is strictly enforced and monitored then the risk of deliberate misuse of the personal information through disclosure to unauthorised third parties seems minimal.

The test will be in the implementation of the Register and having robust monitoring of collection and sharing processes to ensure the intent of the Bill is met. If there are not robust mechanisms then confidence in the register will diminish and this in turn may lead to more

people opting out of the screening program because of their concerns with what will be done with their personal information.

The Bill sets out penalties and this appear to be strong enough to act as a deterrent to the unauthorised use of the information but again their effectiveness will depend on the monitoring system picking up unauthorised activity.

It is important that consumers have the right to opt out of any arrangement that involves their personal information being collected, stored or disclosed. CHF believes that the provisions in the Bill that allows individuals to request that their information is not collected, stored or disclosed by the Register, to opt out of the screening programmes and to nominate health care providers to receive information provide consumers with that control.

It will be important, when the Register is operationalised, that there is appropriate and timely consumer information informing them about the Register and letting them know their rights around opting out and controlling what is done with their personal information. Providing this information is a joint responsibility of Government, health care providers who carry out the screening tasks and encourage consumers to participate and the operators of the register and they need to work together to ensure consumers get the information they need .

There also needs to be transparency about the operation of the Register with reporting on its operations including when there have been breaches.

Conclusion

CHF is aware that many concerns have been raised about the awarding of the contract for the National Register to Telstra Health. However it is clear from the Bill that the Commonwealth is the custodian of the data in the register and as such has the responsibility to ensure that sufficient / stringent privacy safeguards and data governance arrangements are put in place to ensure the information collected is only used for the agreed purposes. This responsibility remains with them regardless of any contractual arrangements to operate the Register. The Bills provide those safeguards . It would be CHF's expectation that the Bill's intent with regard to privacy and data governance is upheld in appropriate provisions in the contractual arrangements in place between the Government and Telstra Health. With these legislative provisions and contractual obligations in place CHF believes the population health benefits exceed the risks and the Register should be established.