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AMA Submission to the Inquiry into the National Cancer Screening Register Bill 2016 and the National Cancer Screening Register (Consequential and Transitional Provisions) Bill 2016

The Australian Medical Association welcomes the opportunity to make a submission to the Community Affairs Legislation Committee's Inquiry into the National Cancer Screening Register Bill 2016 and the National Cancer Screening Register (Consequential and Transitional Provisions) Bill 2016.

The Australian Medical Association noted the introduction of the *National Cancer Screening Register Bill 2016* on 31 August, and that on 4 May 2016 the Australian Government signed a contract with Telstra Health to develop and operate the new National Cancer Screening Register. The AMA welcomes the opportunity for the Senate to scrutinise these Bills. Telstra Health does not have direct previous experience in operating registries of this kind and, as this submission goes on to detail, the registries will contain sensitive and personal health data. This should support the renewed National Cervical Screening Program and the expansion of the National Bowel Cancer Screening Program.

The AMA does not oppose the outsourcing of clinical information registries in principle. The merging of multiple databases containing around 10 million records into one database will allow streamlined invitation and reporting for patients, and practitioners will be able to view the current status of screening with a greater level of confidence.

There has been a lack of transparency around the process for awarding this contract, in particular the timing of the announcement. The awarding of such a contract to an entity that has hitherto had no direct role in establishing or operating a register of this kind sets a challenging and potentially troublesome precedent. The AMA therefore would welcome a detailed explanation and assurance from the Department of Health, as well as independent privacy and data experts, that the entity awarded the contract has the capacity to deliver it as contracted, and that every assurance can be given as to how sensitive health and medical data will be stored, how any potential breaches will be addressed, and what arrangements are to be put in place to manage the transition of nine separate cancer screening registers into a single National Cancer Screening Register. Given the potential commercial value of the data contained in the register,

the AMA would be more comfortable with it being operated by government, a tertiary institution, or not-for-profit entity that has little interest in how the data in the register might otherwise be used. This would go a long way to allaying concerns about the secondary use of data for commercial reasons.

In order for the benefits of a single register to be realised, the AMA calls for the following conditions to be met:

- The registry can interact with various software products that are currently used in medical practice.
- The screening data is held in a secure location, similar to that of other sensitive data held by the Australian Government.
- Patients are able to opt in and out of the registry.
- Medical practitioners and patients are able to access the data free of charge.
- The data and the resulting registry, including all associated intellectual property, is owned by the Commonwealth at the end of the contract.
- De-identified data is published for research and policy development purposes.

Given the scope for registries to impact upon a significant proportion of the Australian population, the AMA advocates that the following criteria should be met when outsourcing clinical information registries:

- The enabling legislation contains highly rigorous and ethical safeguards for privacy, security, and clinical accuracy.
- That data is held in Australia and in a data storage facility that meets government data holding requirements.
- Whilst the register must be interoperable with medical practice software and the My Health Record, that the My Health Record is not the only method of accessing the Registry.
- At the conclusion of the contract, the Commonwealth retains the rights to the registry system and the data contained.
- Practitioners and patients are not charged a fee to access their records or the system.
- That there be no reduction in the public data currently available.

While the AMA does not oppose the outsourcing of clinical registries in principle, we note the risks associated with awarding a contract of this magnitude to a company that has no direct previous experience in undertaking such a task.

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