THE PARLIAMENT OF THE COMMONWEALTH OF AUSTRALIA

HOUSE OF REPRESENTATIVES

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

EXPLANATORY MEMORANDUM

(Circulated by authority of the Minister for Health, The Hon Sussan Ley MP)
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OUTLINE

This Bill, the National Cancer Screening Register (Consequential and Transitional Provisions) Bill 2016 (the Bill), provides for the consequential amendments required and transitional matters associated with the enactment of the National Cancer Screening Register Bill 2016.

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, migrate bowel cancer screening and state and territory cervical screening data to the Register, and mandate reporting of screening information to the Register. The designated cancers for the purpose of the NCSR Bills are cervical cancer and bowel cancer.

On 1 April 2015, approval was given by the Expenditure Review Committee to fund the renewal of the National Cervical Screening Program (NCSP) and establish the Register. This Budget measure implements the evidence-based Medical Services Advisory Committee recommendation to replace the two yearly Pap test with a new five yearly cervical screening test for the NCSP. Once implemented from 1 May 2017, it is estimated these changes will prevent about an additional 140 cervical cancers each year.

Approval has also been given to accelerate the expansion of the National Bowel Cancer Screening Program (NBCSP) to a biennial screening interval for Australians 50-74 years of age by 2020, instead of 2034. Evidence from clinical trials has shown that biennial screening using faecal occult blood testing can prevent 300-500 deaths per year.

The Register will be a national electronic infrastructure for the collection, storage, analysis and reporting of cancer screening data for both the renewed NCSP and the NBCSP, with the ability to be expanded to other cancer screening programs in the future. The Register will facilitate invitations, sending out of test kits, recall and clinical decision-making. It will enable improved software integration with general practice, specialists and pathology laboratories, as well as improved quality and accessibility of data and rate of data capture and data matching. Over time it will help increase program participation rates and the effectiveness of the screening programs. Australia’s organised approach to population-based screening will be underpinned by the Register which has the ability to be expanded to support other cancer screening programs in the future.

Consequential to the National Cancer Screening Register Bill 2016 being enacted, the following legislation needs to be amended to allow disclosure for the purposes of including information in the Register:
• Australian Immunisation Register Act 2015 – to authorise the disclosure of specified information kept on the Australian Immunisation Register to the Register
• Australian Institute of Health and Welfare Act 1987 – to authorise the disclosure of specified information kept by the Australian Institute of Health and Welfare to the Register
• Health Insurance Act 1973 – to authorise the disclosure of specified information to enable the ongoing provision of Medicare enrolment and claim data to the Register.

The Bill also includes a transitional provision that authorises participating states and territories to transfer data from state and territory based cervical screening registers to the Register.

The substantive provisions in Schedule 1 of the Bill will come into effect at the same time as the National Cancer Screening Bill 2016. However, if that clause does not commence the provisions in Schedule 1 do not come into effect at all.

Financial Impact Statement

Nil.
Statement of Compatibility with Human Rights

Prepared in accordance with Part 3 of the Human Rights (Parliamentary Scrutiny) Act 2011

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

This Bill is compatible with the human rights and freedoms recognised or declared in the international instruments listed in section 3 of the Human Rights (Parliamentary Scrutiny) Act 2011.

Overview of the Bill

This Bill provides for the consequential amendments required with the enactment of the National Cancer Screening Register Bill 2016 and deals with consequential and transitional matters arising from the enactment of that Act, and for related purposes.

As part of the 2015-16 Commonwealth Budget, the Australian Government committed to implement a renewed National Cervical Screening Program (NCSP) and establish the National Cancer Screening Register (the Register). The Australian Government has accepted the evidence-based Medical Services Advisory Committee recommendation to replace the two-yearly Pap test with a new five-yearly cervical screening test. Once implemented, these changes will prevent an additional 140 cervical cancers each year.

As part of the 2014-15 Budget, the Australian Government committed to accelerate the expansion of the National Bowel Cancer Screening Program (NBCSP) to a biennial screening interval for Australians 50-74 years of age by 2020. Evidence from clinical trials has shown that biennial screening using faecal occult blood testing can prevent 300-500 deaths per year.

The Register will commence operation on 1 May 2017 and will provide a national electronic infrastructure for the collection, storage, analysis and reporting of cancer screening program data for both the renewed NCSP and the NBCSP. The Register will facilitate invitations, sending out of test kits, recall and clinical decision-making and increase program participations rates and the effectiveness of the screening programs. Australia’s organised approach to population-based screening will be underpinned by the Register which will also have the ability to be expanded to support other cancer screening programs in the future.

Consequential to the National Cancer Screening Register Bill 2016 being enacted, the following legislation is being amended:

- *Australian Immunisation Register Act 2015* – to authorise the disclosure of information kept on the Australian Immunisation Register to the Register.
- *Australian Institute of Health and Welfare Act 1987* – to authorise the disclosure of specified information kept by the Australian Institute of Health and Welfare to the Register.
• Health Insurance Act 1973 – authorise the disclosure of specified information to enable the ongoing provision of Medicare enrolment and claims data to the Register.

This Bill will come into effect the same day that clause 1 of the National Cancer Screening Register Bill 2016 commences.

Human rights implications

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)).

Protection of privacy and reputation

Article 17 of the ICCPR prohibits arbitrary or unlawful interference with an individual’s privacy, family, home and correspondence. For interferences with privacy not to be arbitrary, they must be reasonable in the particular circumstances. Reasonableness, in this context, incorporates notions of proportionality to the end sought and necessity in the circumstances.

The Bill engages Article 17 of the ICCPR by provisions that authorise disclosure of information, including personal information, from the Australian Immunisation Register, Australian Institute of Health and Welfare, Medicare database and state and territory based cervical screening registers.

Clause 1 of Schedule 1 of the Bill amends section 22 of the Australian Immunisation Register Act 2015 to authorise information from the Australian Immunisation Register to be provided to the Register. At present this would encompass the provision of information on the Human Papilloma Virus (HPV) vaccination status of individuals participating in the NCSP. The purpose of sharing this information is so that the Department of Health can undertake analysis on the effectiveness of the HPV vaccine in reducing the rates of cervical cancer.

Clause 3 of Schedule 1 of the Bill amends section 29 of the Australian Institute of Health and Welfare Act 1987 to authorise the provision of information held by the Australian Institute of Health and Welfare (AIHW) to the Register. The purpose of this authorisation is for the Register to be able to obtain information from the National Death Index administered by the AIHW. This will be used by the Register to ensure that individuals who are deceased will not be invited to screen under the NCSP or NBCSP.

Clause 4 of Schedule 1 of the Bill amends section 130 of the Health Insurance Act 1973 to authorise Medicare information to be provided to the Register. This would include individuals’ Medicare enrolment information and certain claims information. The primary purpose for the Register to collect this personal information is to pre-populate the Register with personal information of individuals who are eligible to
participate in the NCSP and the NBCSP so that they can be invited to undergo screening. The provision of Medicare enrolment information to the Register is necessary for identifying those individuals who will be invited to undergo screening and make contact with them or to ensure that the Register has accurate contact details for individuals already participating in the NCSP and NBCSP. The provision of certain Medicare claims information to the Register is also necessary for identifying individuals who should not be invited to undergo screening who would otherwise be eligible.

Clause 6 of Schedule 1 of the Bill is a transitional provision that authorises the states and territories to use and disclose information from the state and territory based cervical screening registers to the Register. Without this authorisation some states and territories may be limited in their ability to transfer information from their cancer screening registers to the Register. The purpose of this authorisation is to ensure that no information is lost in the transition from state and territory based cervical screening registers to the Register.

Once provided to the Register, the information described above will be afforded the protections provided in Part 3 of the National Cancer Screening Register Bill 2016. Individuals’ privacy is maintained and not diminished as clause 17 of the National Cancer Screening Register Bill 2016 imposes limitations on how information in the Register is collected, used and disclosed. Sanctions will apply for unauthorised collection, use and disclosure.

The authorisations for the use and disclosure of personal information to the Register are reasonable, appropriate and necessary for the objectives and purposes of the Bill.

**Right to health**

The Bill engages articles 2 and 12 of the ICESCR by assisting the progressive realisation of the rights of everyone by all appropriate means to the enjoyment of the highest attainable standard of physical and mental health. The Bill assists the advancement of this human right by establishing the Register for the purpose of supporting early detection and prevention of cancer through screening.

The linking of HPV vaccination data with data on the Register will allow analysis of the effectiveness of the HPV vaccine. This will allow the Department of Health to monitor the effectiveness of the HPV vaccine in reducing the rates of cervical cancer.

The transition from state and territory based cervical screening registers to the Register will ensure healthcare providers have access to an individual’s complete screening history when providing healthcare. Currently, if an individual moves states, their cervical screening history may be contained in more than one cervical screening register. This means that a healthcare provider may not have access to an individual’s complete cervical screening history when interpreting screening test results, which in turn may impact on clinical decision-making. The authorisation for the transfer of information from state and territory based cervical screening registers to the Register will therefore assist healthcare providers in their clinical decision-making by enabling access to a complete screening history.
Conclusion

The Bill is compatible with human rights because it advances the protection of human rights as outlined above and to the extent that it may also limit human rights, those limitations are reasonable, necessary and proportionate.

Minister for Health, the Hon Sussan Ley, MP
NOTES ON CLAUSES

Clause 1 – Short Title

This clause provides that the Bill, once enacted, may be cited as the National Cancer Screening (Consequential and Transitional Provisions) Act 2016.

Clause 2 – Commencement

This Clause provides the commencement dates for the provisions in the Bill. The transitional arrangements described in the Bill will facilitate screening program continuity and seamless implementation of the new Register.

Clauses 1 to 3 of the Bill commence the day the Bill receives Royal Assent.

Schedule 1 of the Bill commences at the same time as clause 1 of the National Cancer Screening Register Bill 2016 but does not commence if clause 1 of the National Cancer Screening Register Bill 2016 does not commence at all.

Clause 3 – Schedules

Clause 3 provides that each Act that is specified in the Schedule to this Bill is amended or repealed as set out in the applicable items in the Schedule and that any other items have effect according to their terms.

SCHEDULE 1 – Amendments

Part 1 – Amendments

Australian Immunisation Register Act 2015

1 After paragraph 22(2)(c)

Insertion of paragraph 22(2)(ca) allows protected information in the Australian Immunisation Register to be disclosed to the Register.

This provision enables the collection of HPV vaccination status from the Australian Immunisation Register so that individuals’ cervical screening information in the Register will also include their HPV vaccination status, allowing healthcare providers access to a more complete record of an individual’s medical history. This will also enable the Department of Health to undertake analyses of the effectiveness of the HPV vaccine in preventing cervical cancer.
**Australian Institute of Health and Welfare Act 1987 (AIHW Act)**

2. **At the end of paragraphs 29(2)(a) and (b)**

This amendment is made to the AIHW Act so that all the paragraphs in subsection 29(2) have an “or” on the end.

3. **At the end of subsection 29(2)**

Insertion of paragraph 29(2)(e) authorises a person to provide information for inclusion in the Register.

Such information may include an individual’s date of death so they may be excluded from receiving an invitation for screening or a test kit associated with a designated cancer.

**Healthcare Insurance Act 1973 (HI Act)**

4. **After subsection 130(5G)**

This provision amends the Health Insurance Act 1973 by inserting subsection (5H) to allow for Medicare information to be disclosed to the Register.

The amendment will enable the initial data migration and ongoing provision of Medicare enrolment and claim data to the Register.

The Medicare enrolment and claims data will be used for inviting people to screen, updating details of participants in the NCSP and NBCSP and excluding people who should not undergo screening.

**Part 2–Application and transitional provisions**

5. **Definitions**

Subsection 5(1) provides a definition of the Register as established under Part 2 of the National Cancer Screening Register Bill 2016 and a Register operational date of 1 May 2017. It also inserts the definition of prescribed cervical screening register as a register or database prescribed by the Rules made under subclause 7(3) of this Bill. These definitions are used for the purposes of clauses 7 and 8.

Subsection 5(2) provides that in this Part, an expression used has the same meaning as in the National Cancer Screening Register Bill 2016. This ensures that there is consistency in interpretation of this Bill and the National Cancer Screening Register Bill 2016.

6. **Transfer of information from State and Territory databases**

Clause 6 authorises the transfer of data from states and territory cervical screening registers and databases to enable pre-population of the Register. This is required to
ensure that no information is lost in the transition from state and territory based cervical screening registers to the Register.

Subclause (1) authorises states and territories to use and disclose information in a prescribed cervical screening register to the Commonwealth for the purposes of the including information in the Register.

Subclause (2) specifies that information used or disclosed under subsection (1) is taken to have been obtained under the National Cancer Screening Register Act 2016. This ensures that the information transferred over is covered by the protections in Part 3 of the National Cancer Screening Register Bill 2016.

Subclause (3) allows the Minister to make rules, by way of legislative instrument, prescribing participating state and territory jurisdiction registers or databases which exist under legislation of a participating state or territory and contain information about individuals in connection with screening associated with cervical cancer. This power will be used to identify the types of information in state and territory registers or databases that are authorised for transfer to the Register.

Subclause (4) provides that this section applies despite any existing Commonwealth, state or territory legislation. This means that the states and territories can transfer information despite any laws that might otherwise prohibit the transfer of information from prescribed registers or databases to the Register.

7 Register operation to start on 1 May 2017

Clause 7 deals with the application of the National Cancer Screening Bill 2016 between the time of commencement of the National Cancer Screening Bill 2016 and the operational date (1 May 2017) and the application of the requirement to notify in clause 13 of the National Cancer Screening Bill 2016.

Subclause (1) provides that before the operational date the National Cancer Screening Bill 2016 has effect as if the purposes in paragraphs 12(1)(b) to (n) were not purposes of the Register.

This means that the only purpose of the Register that would be applicable before the operational date is establishing and keeping an electronic database of records relating to screening and diagnosis associated with bowel cancer and cervical cancer. The other purposes, such as providing individuals with test kits, would not be applicable before the operational date and therefore the collection, recording, disclosure or use of protected information would not be authorised for those purposes under subclause 17(3) of the National Cancer Screening Bill 2016.

Subclause (2) provides that subclause 13(2) of the National Cancer Screening Bill 2016, providing for the requirement to notify, does not apply before 1 May 2018. This means that civil penalty proceedings cannot be brought against someone for failure to notify where required to under clause 13 of the National Cancer Screening Bill 2016 prior to 1 May 2018.
Subclause (3) provides that paragraphs 17(3)(b), (c), (d) and (g) of the National Cancer Screening Bill 2016 do not apply to collection, recording, disclosure or use of protected information before the operational date.

This provision will prevent the handling of protected information before the operational date by healthcare providers, state and territory officers or those engaged by the states and territories, those authorised by the Minister for the purposes of specified research or in the public interest and those to whom information has been disclosed for a purpose where the handling would be consistent with that purpose. This ensures more limited handling of protected information prior to the full operation of the Register.