



SENATE STANDING COMMITTEE
FOR THE
SCRUTINY OF BILLS

SEVENTH REPORT
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Terms of Reference

Extract from **Standing Order 24**

- (1) (a) At the commencement of each Parliament, a Standing Committee for the Scrutiny of Bills shall be appointed to report, in respect of the clauses of bills introduced into the Senate or the provisions of bills not yet before the Senate, and in respect of Acts of the Parliament, whether such bills or Acts, by express words or otherwise:
 - (i) trespass unduly on personal rights and liberties;
 - (ii) make rights, liberties or obligations unduly dependent upon insufficiently defined administrative powers;
 - (iii) make rights, liberties or obligations unduly dependent upon non-reviewable decisions;
 - (iv) inappropriately delegate legislative powers; or
 - (v) insufficiently subject the exercise of legislative power to parliamentary scrutiny.
- (b) The committee, for the purpose of reporting on its terms of reference, may consider any proposed law or other document or information available to it, including an exposure draft of proposed legislation, notwithstanding that such proposed law, document or information has not been presented to the Senate.
- (c) The committee, for the purpose of reporting on term of reference (a)(iv), shall take into account the extent to which a proposed law relies on delegated legislation and whether a draft of that legislation is available to the Senate at the time the bill is considered.

SENATE STANDING COMMITTEE FOR THE SCRUTINY OF BILLS

SEVENTH REPORT OF 2016

The committee presents its *Seventh Report of 2016* to the Senate.

The committee draws the attention of the Senate to clauses of the following bills which contain provisions that the committee considers may fall within principles 1(a)(i) to 1(a)(v) of Standing Order 24:

Bills	Page No.
National Cancer Screening Register Bill 2016	433

National Cancer Screening Register Bill 2016

Purpose	This bill creates the legislative framework for the establishment and ongoing management of the National Cancer Screening Register
Portfolio	Health
Introduced	House of Representatives on 31 August 2016 <i>This bill is similar to a bill introduced in the previous Parliament</i>

Alert Digest No. 6 of 2016 - extract

Trespass on personal rights and liberties—privacy

General comment

Clause 11 of the bill provides for the proposed National Cancer Screening Register to include certain key information about individuals, including personal identifying information, and information about individuals' screening tests, diagnosis with a designated cancer or precursor to a designated cancer, and nominated healthcare provider. The statement of compatibility (at p. 4) states that these authorised collections, recordings, uses and disclosures are designed 'to ensure that the National Cervical Screening Program and the National Bowel Cancer Screening Program function effectively by allowing the appropriate sharing of information'. The consequences of the bill for privacy interests are set out in the statement of compatibility at pages 4–5.

Clause 14 of the bill allows individuals to opt out of participation in the screening programs. The explanatory memorandum (at p. 19) states that:

Individuals may elect to opt off from, or defer, receiving invitations to screen, test kits, or reminders to rescreen or undergo follow-up tests or procedures. Individuals may also elect not to have information relating to their screening test or diagnosis recorded in the Register.

An individual may opt-off from or defer screening for a designated cancer by using the Register self-service facility, contacting the register operator, or during a

consultation with their healthcare provider. Individuals have the option to opt-off screening for a designated cancer at any point and opt back in whenever they choose.

Paragraph 14(1)(c) of the bill allows an individual to elect not to have information notifiable under clause 13 included in the Register. In relation to this paragraph, the explanatory memorandum (at p. 19) notes that:

This provision operates prospectively, that is, any information related to the individual that has already been collected by the Register prior to receiving the request from the individual will remain in the Register. This will allow consistent, complete and accurate data for reporting and statistical purposes to ensure Register data is not compromised by retrospective removal of information.

The committee notes the options available to opt out of participation, but in light of the potential impact of this bill on the privacy interests of individuals the committee seeks the Minister's advice as to:

- **whether consideration was given to framing the register as an opt-in initiative (for example, by allowing doctors and other health care professionals to include their patients on the register after receiving their consent), rather than requiring individuals to actively opt-out; and**
- **the rationale for not allowing individuals to elect to have all their information removed from the Register under paragraph 14(1)(c) of the bill (for example, the committee seeks further information as to how retrospective removal of information would compromise Register data).**

Pending the Minister's reply, the committee draws Senators' attention to this bill as it may be considered to trespass unduly on personal rights and liberties in breach of principle 1(a)(i) of the committee's terms of reference.

Minister's response - extract

The Register is national electronic infrastructure that will record and maintain details about individuals' screening test results and diagnoses associated with cervical cancer and bowel cancer. It will replace the existing bowel cancer screening register, operated by the Department of Human Services, as well as the eight state and territory cervical screening registers supporting the National Cervical Screening Program (NCSP), at the discretion of each state and territory.

Register data will be used for the purposes of identifying participants' eligibility and screening history to support real time decision making and to encourage participants to progress along the bowel and cervical screening pathways. The Register will address privacy concerns associated with the collection, recording of, use and disclosure of individuals' information in several ways. For example, the screening programs' respective

web sites and the Register portal will clearly communicate the individual's right to opt off or defer participation in the Register and provide options on how to do so. Screening correspondence sent to individuals will provide clear messages about calling the Contact Centre, visiting the Register's participant portal, or providing verbal consent to their healthcare provider to complete the form on their behalf during a consultation - should they not wish to participate in the Register.

Paragraph 14(1)(c) provides that, if desired, an individual can request that their information, which is notifiable to the Commonwealth Chief Medical Officer in accordance with clause 13 of the NCSR Bill, not be included in the Register. As the provision does not operate retrospectively, the individual's data that is already held in the Register prior to the date of the request will not be deleted from the Register. You have asked in relation to paragraph 14(1)(c) whether consideration was given to establishing the Register as an opt-in rather than opt-off register.

I can confirm that prior to my 2015-16 Budget announcement on 10 May 2015 concerning new legislation that would be created to establish the Register, my Department considered an opt-in model for the Register where the collection, use and disclosure of individuals' screening information would be based on the consent of individuals. However, in order to support this Government's commitment to improve cancer detection, treatment and prevention, it was considered that a single, cost effective opt-off system that uses a whole of population baseline from which to commence the renewed NCSP and expanded National Bowel Cancer Screening Program would deliver better outcomes for these screening programs and greater potential to save lives. It should be noted that the existing bowel cancer screening register and the eight state and territory cervical screening registers all operate on an opt-off basis.

You have also asked for advice on the rationale for the Register not allowing retrospective removal of data for individuals who opt-off. One of the purposes of the Register is to facilitate the collection, analysis and publishing of statistics and other information relating to cervical and bowel cancer screening. To this end, Register data will be used for analytical purposes at a population level to monitor program performance, compliance with annual quality and safety monitoring activities and to analyse population data trends. In relation to paragraph 14(1)(c), once a participant opts off the Register, no further data will be recorded and the individual's retrospective screening history will remain in the database but be hidden from view to protect the person's privacy. In this regard, I note that individuals can also request that a pseudonym be used in connection with their record in the Register. These measures ensure a balance is maintained between individuals' personal privacy and public trust that the information held in the Register is valid, complete and reliable in delivering quality health and safety outcomes for both screening programs.

I note the Committee has sought further information as to how retrospective removal of information would compromise Register data. Retrospective deletion of individuals' screening information from the Register can lead to inconsistent reporting and have a significant effect on the validity of the conclusions that are drawn. For example, removal of data that has already been included in population trends analysis may compromise the

Register's data quality and integrity as research results will differ from publically released annual program reports. This in turn will impact the credibility of both screening programs as well as program and policy evaluations into the future.

Committee response

The committee thanks the Minister for this detailed response.

The committee notes Minister's advice in relation to the rationale for proceeding with an opt-out, rather than an opt-in, Register.

In relation to the rationale for not allowing individuals to elect to have all their existing information removed from the Register, the committee notes the Minister's advice that once a person opts out of the Register the individual's retrospective screening history will remain in the database but be hidden from view to protect the person's privacy. The committee also notes the Minister's advice that retrospective deletion of individual's screening information from the Register could lead to inconsistent reporting and have a significant effect on the validity of conclusions drawn. However, the committee reiterates that the retention of personal information, in circumstances where a person would have preferred all information pertaining to them to be removed from the Register, represents a significant impact on the privacy interests of those individuals.

The committee requests that the key information provided in the Minister's response be included in the explanatory memorandum, noting the importance of these documents as a point of access to understanding the law and, if needed, as extrinsic material to assist with interpretation—see section 15AB of the *Acts Interpretation Act 1901*.

In light of the detailed advice provided, the committee leaves the question of whether the proposed approach to the protection of individuals' privacy interests is appropriate to the consideration of the Senate as a whole.

Alert Digest No. 6 of 2016 - extract

Trespass on personal rights and liberties—privacy

Inappropriate delegation of legislative power

Subclause 11(g)

Subclause 11(g) provides that the register may include further information relevant to the purposes of the register and prescribed by the rules. The explanatory memorandum suggests that providing this level of flexibility is necessary as 'rapidly advancing

technology or changes in screening tests' may mean that 'the range of information that needs to be collected may also change and is difficult to predict' (at p. 14).

Although the need for some flexibility in light of changing technology may be accepted, **the committee seeks the Minister's advice as to whether consideration has been given to including in the bill a specific requirement to consult the Privacy Commissioner prior to the making of rules under subclause 11(g).**

Pending the Minister's reply, the committee draws Senators' attention to the provision, as it may be considered to trespass unduly on personal rights and liberties and to delegate legislative powers inappropriately, in breach of principles 1(a)(i) and 1(a)(iv) of the committee's terms of reference.

Minister's response - extract

Subclause 11(g) provides that the Register may include any other information relevant to the purposes of the Register and prescribed in the rules. You have asked whether consideration was given to requiring consultation with the Privacy Commissioner prior to the making of rules under this subclause. I agree that this provision should be amended to include a specific requirement to consult the Privacy Commissioner prior to the making of the rules as a safeguard to ensure any new classes of information will not unreasonably interfere with individuals' privacy.

Committee response

The committee thanks the Minister for this response.

The committee welcomes the Minister's undertaking to amend the bill to include a specific requirement to consult the Privacy Commissioner prior to the making of rules as a safeguard to ensure any new classes of information to be collected as part of the Register will not unreasonably interfere with individuals' privacy.

The committee also draws this provision to the attention of the Regulations and Ordinances Committee for information.

In light of the proposed amendment and the fact that any rule made under the provision will be subject to Parliamentary scrutiny and disallowance, the committee makes no further comment in relation to this provision.

Alert Digest No. 6 of 2016 - extract

Trespass on personal rights and liberties—privacy Inappropriate delegation of legislative power Subparagraph 17(3)(a)(iv)

Subparagraph 17(3)(a)(iv) authorises a person to collect, make a record of, disclose or otherwise use protected information for the purposes of the Register if that person is a ‘prescribed body’.

As there is no explanation for the inclusion of this provision in the explanatory materials accompanying the bill, the committee seeks the Minister’s advice as to:

- **the rationale for, and necessity of, this provision; and**
- **how adequate control over personal information is to be maintained in relation to these (yet to be determined) prescribed bodies.**

Pending the Minister’s reply, the committee draws Senators’ attention to the provision, as it may be considered to trespass unduly on personal rights and liberties and to delegate legislative powers inappropriately, in breach of principles 1(a)(i) and 1(a)(iv) of the committee’s terms of reference.

Minister’s response - extract

Subparagraph 17(3)(a)(iv) authorises a person to collect, make a record of, disclose or otherwise use protected information or key information for the purposes of the Register if that person is a ‘prescribed body’. You have asked for advice on the rationale for, and necessity of, this provision. On further consideration, it is unlikely that subparagraph 17(3)(a)(iv) would be required for prescribing other bodies who are authorised to collect, make a record of, disclose or use protected information or key information for the purposes of the Register in the future. Therefore, I agree that this provision be removed from the NCSR Bill.

I have instructed my Department to make the above amendments to the NCSR Bill and trust that the changes are sufficient to address the Committee’s concerns.

Committee response

The committee thanks the Minister for this response.

The committee welcomes the Minister's undertaking to amend the bill to remove subparagraph 17(3)(a)(iv) which authorises a person to collect, make a record of, disclose or otherwise use protected information for the purposes of the Register if that person is a 'prescribed body'.

In light of the proposed amendment the committee makes no further comment in relation to this provision.

Senator Helen Polley
Chair



**THE HON SUSSAN LEY MP
MINISTER FOR HEALTH AND AGED CARE
MINISTER FOR SPORT**

Ref No: MC16-029188

Senator Helen Polley
Chair
Senate Scrutiny of Bills Committee
Suite 1.111
Parliament House
CANBERRA ACT 2600

Dear Chair

Thank you for your correspondence of 15 September 2016 seeking information concerning paragraph 14(1)(c), subclause 11(g) and subparagraph 17(3)(a)(iv) of the National Cancer Screening Register Bill 2016 (the NCSR Bill).

The Register is national electronic infrastructure that will record and maintain details about individuals' screening test results and diagnoses associated with cervical cancer and bowel cancer. It will replace the existing bowel cancer screening register, operated by the Department of Human Services, as well as the eight state and territory cervical screening registers supporting the National Cervical Screening Program (NCSP), at the discretion of each state and territory.

Register data will be used for the purposes of identifying participants' eligibility and screening history to support real time decision making and to encourage participants to progress along the bowel and cervical screening pathways. The Register will address privacy concerns associated with the collection, recording of, use and disclosure of individuals' information in several ways. For example, the screening programs' respective web sites and the Register portal will clearly communicate the individual's right to opt off or defer participation in the Register and provide options on how to do so. Screening correspondence sent to individuals will provide clear messages about calling the Contact Centre, visiting the Register's participant portal, or providing verbal consent to their healthcare provider to complete the form on their behalf during a consultation - should they not wish to participate in the Register.

Paragraph 14(1)(c) provides that, if desired, an individual can request that their information, which is notifiable to the Commonwealth Chief Medical Officer in accordance with clause 13 of the NCSR Bill, not be included in the Register. As the provision does not operate retrospectively, the individual's data that is already held in the Register prior to the date of the request will not be deleted from the Register. You have asked in relation to paragraph 14(1)(c) whether consideration was given to establishing the Register as an opt-in rather than opt-off register.

I can confirm that prior to my 2015-16 Budget announcement on 10 May 2015 concerning new legislation that would be created to establish the Register, my Department considered an opt-in model for the Register where the collection, use and disclosure of individuals' screening information would be based on the consent of individuals. However, in order to support this Government's commitment to improve cancer detection, treatment and prevention, it was considered that a single, cost effective opt-off system that uses a whole of population baseline from which to commence the renewed NCSP and expanded National Bowel Cancer Screening Program would deliver better outcomes for these screening programs and greater potential to save lives. It should be noted that the existing bowel cancer screening register and the eight state and territory cervical screening registers all operate on an opt-off basis.

You have also asked for advice on the rationale for the Register not allowing retrospective removal of data for individuals who opt-off. One of the purposes of the Register is to facilitate the collection, analysis and publishing of statistics and other information relating to cervical and bowel cancer screening. To this end, Register data will be used for analytical purposes at a population level to monitor program performance, compliance with annual quality and safety monitoring activities and to analyse population data trends. In relation to paragraph 14(1)(c), once a participant opts off the Register, no further data will be recorded and the individual's retrospective screening history will remain in the database but be hidden from view to protect the person's privacy. In this regard, I note that individuals can also request that a pseudonym be used in connection with their record in the Register. These measures ensure a balance is maintained between individuals' personal privacy and public trust that the information held in the Register is valid, complete and reliable in delivering quality health and safety outcomes for both screening programs.

I note the Committee has sought further information as to how retrospective removal of information would compromise Register data. Retrospective deletion of individuals' screening information from the Register can lead to inconsistent reporting and have a significant effect on the validity of the conclusions that are drawn. For example, removal of data that has already been included in population trends analysis may compromise the Register's data quality and integrity as research results will differ from publically released annual program reports. This in turn will impact the credibility of both screening programs as well as program and policy evaluations into the future.

Subclause 11(g) provides that the Register may include any other information relevant to the purposes of the Register and prescribed in the rules. You have asked whether consideration was given to requiring consultation with the Privacy Commissioner prior to the making of rules under this subclause. I agree that this provision should be amended to include a specific requirement to consult the Privacy Commissioner prior to the making of the rules as a safeguard to ensure any new classes of information will not unreasonably interfere with individuals' privacy.

Subparagraph 17(3)(a)(iv) authorises a person to collect, make a record of, disclose or otherwise use protected information or key information for the purposes of the Register if that person is a 'prescribed body'. You have asked for advice on the rationale for, and necessity of, this provision. On further consideration, it is unlikely that subparagraph 17(3)(a)(iv) would be required for prescribing other bodies who are authorised to collect, make a record of, disclose or use protected information or key information for the purposes of the Register in the future. Therefore, I agree that this provision be removed from the NCSR Bill.

I have instructed my Department to make the above amendments to the NCSR Bill and trust that the changes are sufficient to address the Committee's concerns.

Thank you for bringing these matters to my attention.

Yours sincerely



The Hon Sussan Ley MP

4 OCT 2016