



Australian Government

NATIONAL
CANCER
SCREENING
REGISTER

National Cancer Screening Register

Privacy Policy

www.ncsr.gov.au

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1. About this policy

The National Cancer Screening Register (the **National Register**) is a national electronic infrastructure for the collection, storage, analysis and reporting of cancer screening program data for the National Cervical Screening Program and the National Bowel Cancer Screening Program.

The National Register aims to create better healthcare services for our community in relation to cervical and bowel cancer. Through screening, the National Register supports the early detection of changes that may lead to these cancers, as well as facilitates clinical decision making about cervical and bowel cancer.

This Privacy Policy describes why, when, and how we collect, use and disclose your information to operate the National Register.

The Australian Government Department of Health (**Health**) is the custodian of the information in the National Register and has contracted Telstra Corporation Limited (**Contracted Service Provider**) to build and operate the National Register. When this Privacy Policy mentions **us**, **we** or **our**, it refers to Health and the Contracted Service Provider who takes actions on behalf of Health.

2. Privacy

We have obligations in relation to personal information about individuals (**you, your**).

We are bound by the *Privacy Act 1988* (Cth) (the Privacy Act), including the Australian Privacy Principles (APPs), and the *National Cancer Screening Register Act 2016* (the NCSR Act). These Acts regulate how we collect, record, use, store and disclose information we hold about you and to whom it can be released.

When we collect personal information about you, we have obligations under the Privacy Act to notify you or your personal representative (if you have one) about a number of matters, including why we are collecting the information. We generally provide this notification by having Privacy Notices on our paper-based forms, electronic messages and correspondence to you and online portals.

Privacy Impact Assessment

In December 2016, a **Privacy Impact Assessment** (PIA) for the National Register was conducted for Health to assess the National Register's impact on the privacy of individuals and made recommendations for managing, minimising or eliminating that impact. The PIA recommended that Health develop a privacy policy for the National Register.

3. Collection use and disclosure of personal information

Collecting your personal information

Individuals

We collect information about you for the purposes of the National Register. We collect personal information so that we can identify you and administer the functions of the National Register.

We collect information about you that is related to cervical and bowel screening, such as:

- your history of screening, for example, the date of your last cervical screening test and/or when we last sent you a bowel cancer screening kit
- your history of assessment and diagnosis and any test results, for example your biopsy results following a positive cervical screening test, or if lesions or other abnormalities were found as a result of a colonoscopy, following a positive bowel screening test.
- information about your vaccination status for human papillomavirus (HPV)
- key information about you such as your address, contact details, date of birth, gender, Medicare number, individual healthcare identifier and information about any assistance you require due to a medical condition or disability.

We collect personal information about you from various sources such as Services Australia (formerly the Department of Human Services), (for example, Medicare claims information showing that you have undertaken services relevant to bowel and cervical cancer screening), the Department of Veterans' Affairs (DVA) (for example individual DVA numbers), healthcare providers (for example, test results) and state and territory health departments. We may also collect personal information directly from you, your personal representative or a third party.

We also collect sensitive information about you such as your status as an Aboriginal or Torres Strait Islander and racial or ethnic origin to assist in improving the delivery of our cancer screening programs. We only use this information for research and reporting purposes.

We may collect other information about you relevant to the purposes of the National Register if they are prescribed under the NCSR Act.

Table 1 at Appendix A summarises the types of information we collect, the sources of data and the purposes of the collection of information.

Personal representatives

A personal representative may be appointed to act on your behalf in relation to the National Register (refer to [Part 4 – Your participation in the National Register](#)). Your personal representative will be able to elect to receive correspondence (invitation to screen, reminders or follow-ups) on your behalf, or obtain information about cervical or bowel screening, including your screening test results, on your behalf.

If you are a personal representative of an individual in the National Register, we collect information about you to confirm your identity and administer the functions of the National Register on behalf of the person you represent.

Healthcare providers

If you are a healthcare provider, we may also collect information about you from individuals who have nominated you as their healthcare provider, other healthcare providers (e.g. pathology providers and specialists), Services Australia, the National Health Service Directory, PRODA and Endpoint Locator Service.

Table 2 at Appendix A summarises the types of information we collect about healthcare providers, the sources of data and the purposes of the collection of information.

Using and disclosing your information

We will only use and disclose information about you for the purposes of the National Register or as authorised by the NCSR Act.

Table 3 at Appendix A summarises the types of information we disclose, who we disclose that information to, the purpose of disclosure and how the information may be used.

Other authorised uses and disclosures under the NCSR Act include:

- to a professional disciplinary authority, a child protection officer or an enforcement body if the information will enable or assist in performing or exercising the authority's, officer's or body's functions or powers
- for court or tribunal proceedings or in accordance with an order of a court or tribunal
- for a coronial inquiry or in accordance with an order of a coroner
- for research that complies with the Guidelines made under sections 95 and 95A of the Privacy Act (as applicable)
- use or disclosure by a state or territory authority where the use or disclosure is required or permitted by that state's or territory's law.

Information we collect may be used or disclosed for quality assurance, to improve the National Register and for health promotion and planning purposes.

Unsolicited personal information

In some cases, we may receive unsolicited information about you that is not relevant to the National Register's functions or purposes.

If we do receive personal information in these circumstances, we must determine whether we could have lawfully collected the information. If we could not, we will destroy the information or de-identify it if it is lawful and reasonably practicable to do so.

4. Your participation in the National Register

You or your personal representative may make any of the following requests regarding your participation in the National Register:

- You may nominate a healthcare provider for the cervical or bowel program. Your nominated healthcare provider will be advised when you are overdue for follow-up action.
- You may request us to not contact you or send you any correspondence (including an invitation to screen or reminder or follow-up letters) for a selected period of time or not at all.
- You may request to defer or change the date you are due to undergo a screening test.
- You may request to use a pseudonym when interacting with the National Register.

- You may choose to not participate in the National Register and opt-out. If you do:
 - We will not collect any of your cervical or bowel screening test results or any related test and diagnosis information after the date we process your request to not participate in the National Register.
 - We will not send you any correspondence (including an invitation to screen or reminder or follow-up letters).
 - Your historical clinical information will be made inaccessible from the date of your request and will only become accessible again if you decide to participate in the National Register at a later stage.

Demographic information (for example, your name, address, date of birth and Medicare number) will still be collected about you for the purposes of verifying your information to ensure the National Register does not collect any new clinical information about you. This demographic information will not be used or disclosed outside of this purpose. To understand the implications of opting out or what happens when you choose not to participate in the National Register, please see [Information about opting out of the National Register](#).

You may request your personal representative (if you have one) or your healthcare provider to make any of the above requests on your behalf.

You may also withdraw any request concerning your participation at any time. Your personal representative (if you have one) or your healthcare provider may withdraw a request on your behalf.

To make any of the above requests regarding participation in the National Register, you can visit the [National Cancer Screening Register website](#).

When we receive a request about your participation in the National Register or withdrawal of a previous request, from you or your personal representative, we will action it as soon as practicable.

5. Storage and security of your personal information

We take all reasonable steps to maintain systems and procedures to ensure that the personal information we hold is protected against misuse, interference and loss from unauthorised access, modification or disclosure.

These steps include:

- ensuring secure storage of personal information in accordance with Australian Government security policies and guidelines, including the *Attorney-General's Department Protective Security Policy Framework* and the *Australian Signals Directorate Information Security Manual*
- granting access to personal information to authorised personnel only
- monitoring system access and authenticating credentials
- updating and auditing our storage and data security systems regularly.

Your information in the National Register is stored within Australia in secure data storage facilities.

Storage of personal information (and the disposal of information when no longer required) is managed in accordance with the *Archives Act 1983* and relevant Records Authorities and General Disposal Authorities.

6. Accidental or unauthorised disclosure of personal information

Information held in the National Register may only be used and disclosed in accordance with the NCSR Act.

We have an obligation to comply with the data breach notification requirements in the NCSR Act and the Privacy Act. Any potential or actual unauthorised access, use, recording or disclosure of personal information will be taken seriously and dealt with promptly.

Unauthorised access, use, recording or disclosure of personal information held in, or derived from, the National Register is an interference with the privacy of an individual and is an offence under the NCSR Act.

This offence has a penalty of imprisonment for two years or 120 penalty units, or both. Exceptions to the penalty apply in certain limited circumstances.

7. Cookies

Cookies are small pieces of information that are stored by your browser on your device. They are often used as a way for websites to remember useful information, and can contribute to ease of use when navigating a website.

Our cookies do not identify you personally; however, they are used to make your browsing experience better.

We use Google Analytics in connection with our website and Google may set cookies on your browser or read cookies that are already there. For more information about how Google uses cookies in relation to our website, please see www.google.com/policies/privacy/partners.

8. Correction of personal information

We will take steps to ensure that the personal information we hold is accurate, up to date and complete. These steps include maintaining and updating personal information when you advise us that your personal information has changed and at other times as necessary.

You can ask us for access to your personal information or to change it. However, the Privacy Act sets out circumstances in which we can decline access to or correction of personal information (e.g. where access is unlawful under the NCSR Act). If we decline your request, we will tell you why.

To access or seek correction of personal information we hold about you, please contact our Privacy Contact Officer whose details are provided in [Part 10 - Who is responsible for this policy?](#)

If you believe your clinical details are incorrect in the National Register, you should contact your healthcare provider. Your healthcare provider, in turn, can notify us about whether or not the information should be corrected. We will deal with each request regarding incorrect clinical information and notify you of the outcome.

9. Access to personal information

You can also request access to documents containing your own personal information by emailing our Freedom of Information (FOI) Unit at foi@health.gov.au. There is no charge under the *Freedom of Information Act 1982* for requesting access to your own personal information. More information about making FOI requests is available on our [FOI web page](#) or by contacting (02) 6289 1666.

10. Complaints

How we handle complaints

If you have a complaint about the way in which we have handled your personal information, you should write to our Privacy Contact Officer whose details are provided in [Part 10 - Who is responsible for this policy?](#)

We will respond promptly to your complaint or request if you provide your contact details. We are committed to the quick and fair resolution of any complaints and will ensure your complaint is taken seriously.

We will respond to your privacy concern or complaint within 30 days from the date that we receive it. We will notify you if we cannot respond to you within this timeframe.

Making a privacy complaint

You also have the option of contacting the Office of the Australian Information Commissioner (OAIC) if you wish to make a privacy complaint, or if you are not satisfied with how we have handled your complaint.

The Australian Information Commissioner is the statutory office-holder responsible for the regulation of privacy laws in Australia in accordance with the *Privacy Act*. The [OAIC website](#) contains more information about the *Privacy Act*, including the APPs, and information about how to make a privacy complaint.

Please note that the OAIC generally requires that a complaint first be raised with us before they will investigate the complaint.

11. Who is responsible for this policy?

Our Privacy Contact Officer is responsible for this policy and can help with queries about:

- how your personal information is collected, held, used or disclosed
- this Privacy Policy
- how to obtain access to, or seek correction of, your personal information

You can contact our Privacy Contact Officer through the following:

Phone: (02) 6289 1555 or freecall 1800 020 103
Online: The online enquiries form at www.health.gov.au
Email: privacy@health.gov.au
Post: Department of Health
GPO Box 9848
CANBERRA ACT 2601

12. Privacy Policy updates

This Privacy Policy will be reviewed regularly and updated as required. This Privacy document is current as at 29 July 2020.

13. Availability of this policy

If you wish to access this Privacy Policy in an alternative format (e.g. hard copy) please contact our Privacy Officer using the contact details provided at [Part 10 - Who is responsible for this policy?](#) of this Privacy Policy.

This Privacy Policy is available free of charge.

The Department of Health's Privacy Policy can be found on the [Department's website](#).

14. Appendix A

Types of information collected and purposes of collection, use and disclosure

Initially, individuals' information was migrated from state and territory cervical screening registers and the Services Australia National Bowel Cancer Screening Register in order to build the National Register. This included individuals' demographic information, Medicare numbers and other information in relation to cervical and bowel cancer (e.g. diagnosis and screening test results). Table 1 below provides information on the purposes of collecting individuals' information on an ongoing basis.

Table 1 - Purposes of collection of individuals' information

Type of information collected	Data source	Purpose of collection
Your name, address, contact details, date of birth, sex, gender and your healthcare provider	<p>Services Australia</p> <p>From you or your personal representative</p> <p>Your healthcare provider; includes pathology providers and specialists</p>	<p>Verify your participant details to enable data matching</p> <p>Provide you (or your personal representative) access to the National Register so you can update your contact and demographic details directly into the National Register, or tell us your preferred method of receiving communications from the National Register. For more information on personal representatives, refer to this Privacy Policy, Part 3 - Collection, use and disclosure of personal information</p> <p>Invite you to cervical screening</p> <p>Invite you to participate in bowel screening, by sending you a bowel test kit</p> <p>Identify if and when you might need a screening test and to invite you to screen, or to determine whether you should not be invited to screen</p> <p>Send you a reminder for cervical screening or to complete your bowel test kit</p> <p>Communicate with your healthcare provider or nominated healthcare provider (if you have one) when you are due to undergo screening or if follow-up action is required as a result of a cervical or bowel cancer screening test</p> <p>Encourage you through your healthcare provider to participate in cervical or bowel cancer screening</p>

		Keep a database of records relating to cervical and bowel cancer screening and diagnoses.
Medicare number	Services Australia	<p>Verify your participant details to enable data matching</p> <p>Identify if and when you might need a screening test and to invite you to screen or re-screen, or to determine whether you should not be invited to screen</p> <p>Keep a database of records relating to cervical and bowel cancer screening and diagnoses.</p>
Medicare enrolment data, including demographic information	Services Australia	<p>Verify your participant details, including contact information, to enable data matching</p> <p>Identify if and when you might need a screening test and to invite you to screen or re-screen, or to determine whether you should not be invited to screen</p> <p>Keep a database of records relating to cervical and bowel cancer screening and diagnoses</p>
Medicare claims information, e.g. to determine whether you have undertaken a procedure relating to cervical or bowel screening	Services Australia	<p>Verify your participant details to enable data matching</p> <p>Identify if and when you might need a screening test and to invite you to screen or re-screen, or to determine whether you should not be invited to screen</p> <p>Send you a reminder for cervical screening or to complete your bowel test kit</p> <p>Assist with follow up of abnormalities detected in your screening test result</p> <p>Keep a database of records relating to cervical and bowel cancer screening and diagnoses</p>
Screening test results (cervical and bowel)	<p>Your healthcare provider or specialist (e.g. colposcopist or colonoscopist)</p> <p>Pathology providers</p> <p>Hospitals, doctors and medical specialists to</p>	<p>Record your clinical history to help support clinical decision making, including maintaining up-to-date information about your screening activity and status to ensure progression along the clinical pathway</p> <p>Advise your healthcare provider when you are due to undergo cervical or bowel cancer screening, or when follow-up action may be</p>

	<p>whom you may be referred</p>	<p>needed after you have undergone cervical or bowel cancer screening</p> <p>Send you a reminder for cervical screening or to complete your bowel test kit</p> <p>Collect, analyse and publish statistics and other information about cervical and bowel cancer screening (de-identified data only)</p> <p>Monitor the effectiveness, quality and safety of cervical and bowel cancer screening</p> <p>Plan, deliver and promote healthcare and services relating to cervical and bowel cancer screening</p> <p>Assist you to receive appropriate follow up and access to health services in accordance with clinical guidelines</p> <p>Keep a database of records relating to cervical and bowel cancer screening and diagnoses</p>
<p>Diagnosis of cervical or bowel cancer or precursor to cervical or bowel cancer</p>	<p>Your healthcare provider or specialist (e.g. colposcopist or colonoscopist)</p> <p>Pathology providers</p> <p>Hospitals, doctors and medical specialists to whom you have been referred-</p>	<p>Record your clinical history to help support clinical decision making, including maintaining up-to-date information about your screening activity and status to ensure progression along the clinical pathway</p> <p>Advise your healthcare provider when follow up action may be needed after you have undergone cervical or bowel cancer screening</p> <p>Collect, analyse and publish statistics and other information about cervical and bowel cancer screening (de-identified data only)</p> <p>Monitor the effectiveness, quality and safety of cervical and bowel cancer screening</p> <p>Plan, deliver and promote healthcare and services relating to cervical and bowel cancer screening</p> <p>Keep a database of records relating to cervical and bowel cancer screening and diagnoses</p>
<p>Human papillomavirus (HPV) vaccination status (if applicable),</p>	<p>National HPV Vaccination Program Register</p>	<p>Monitor the effectiveness, quality and safety of the National HPV Vaccination Program in reducing the incidence of cervical abnormalities and cervical cancer</p>

<p>including doses of the vaccine administered</p>		<p>Collect, analyse and publish statistics and other information about cervical screening (de-identified data only)</p> <p>Monitor the effectiveness, quality and safety of cervical screening</p> <p>Keep a database of records relating to cervical screening and diagnoses</p>
<p>Adverse Events from previous procedures including type of procedure, and any adverse outcomes (bowel)</p>	<p>Your healthcare provider or specialist (e.g. colonoscopist)</p> <p>Pathology providers</p> <p>Hospitals, doctors and medical specialists to whom you may be referred</p>	<p>Collect, analyse and publish statistics and other information about bowel screening (de-identified data only)</p> <p>Monitor the effectiveness, quality and safety of bowel screening and the bowel cancer treatment pathway</p> <p>Keep a database of records relating to bowel screening, diagnoses and treatment</p>
<p>Healthcare identifier</p>	<p>Healthcare Identifiers Service Operator</p> <p>Healthcare providers</p>	<p>Verify your participant details to enable data matching</p>
<p>Department of Veterans' Affairs (DVA) number</p>	<p>Services Australia</p> <p>DVA</p> <p>Healthcare providers</p>	<p>Verify your participant details, including up-to-date contact information, to enable data matching</p> <p>Identify if and when you might need a screening test and to invite you to screen or re-screen, or to determine whether you should not be invited to screen</p> <p>Keep a database of records relating to cervical and bowel cancer screening and diagnoses</p>
<p>Indigenous status</p>	<p>Services Australia</p> <p>From you or your personal representative</p> <p>From your healthcare provider or specialist (e.g. colposcopist or colonoscopist)</p> <p>Pathology providers</p>	<p>Allow accurate measurement of screening participation rates and help the government develop programs that address the barriers to screening participation</p> <p>Identify the Indigenous status of people accessing health services to help Close the Gap in health outcomes between Indigenous and non-Indigenous Australians (de-identified data only)</p> <p>Collect, analyse and publish statistics and other information about cervical and bowel cancer screening (de-identified data only)</p>

		<p>The NCSR may collect Indigenous status about you from a variety of sources (e.g. Medicare, DVA or other means). Where the NCSR holds evidence that you have ever identified as Indigenous, this status will be used for reporting purposes only.</p> <p>Plan, deliver and promote healthcare and services relating to cervical and bowel cancer screening</p> <p>Keep a database of records relating to cervical and bowel cancer screening and diagnoses</p>
<p>Your country of origin and/or your cultural identity, including if you speak another language at home or your preferred language</p>	<p>Services Australia</p> <p>From you or your personal representative</p> <p>From your healthcare provider or specialist (e.g. colposcopist or colonoscopist)</p> <p>Pathology providers</p>	<p>Assist service providers to identify if you require an interpreter or a personal representative when accessing screening services</p> <p>Allow accurate measurement of screening participation rates and help the government develop programs that address the barriers to screening participation</p> <p>Collect, analyse and publish statistics and other information about cervical screening (de-identified data only)</p> <p>The NCSR may collect this information about you from a variety of sources (e.g. Medicare, DVA or other means). Where the NCSR holds evidence that you have ever supplied this information, it will be used for reporting purposes only.</p> <p>Plan, deliver and promote healthcare and services relating to cervical and bowel cancer screening</p> <p>Keep a database of records relating to cervical and bowel cancer screening and diagnoses</p>
<p>If you require an interpreter or assistance to manage medical conditions or disabilities.</p>	<p>From your personal representative</p> <p>From your healthcare provider or specialist (e.g. colposcopist or colonoscopist)</p>	<p>Facilitate communication with you through your interpreter</p> <p>Identify any assistance you may require because of a medical condition or disability</p> <p>Keep a database of records relating to cervical or bowel cancer screening and diagnoses</p>
<p>Details of your personal</p>	<p>From you or your personal representative</p>	<p>Communicate with your personal representative in relation to your participation on the National Register. For more information on personal</p>

representative		representatives, refer to Part 3 - Collection, use and disclosure of personal information
Date of death	<p>Services Australia</p> <p>Personal representative</p> <p>From your healthcare provider or specialist (e.g. colposcopist or colonoscopist)</p>	<p>Verify participant details</p> <p>Ensure correspondence relating to cervical or bowel cancer screening, including test kits, are no longer sent</p> <p>Collect, analyse and publish statistics and other information about cervical and bowel cancer screening (de-identified data only)</p> <p>Keep a database of records relating to cervical and bowel cancer screening and diagnoses</p>
<p>Requests about your participation in the National Register</p> <p>Withdrawal of a previous request about your participation in the National Register</p>	<p>From you or your personal representative</p> <p>From your healthcare provider or specialist (e.g. colposcopist or colonoscopist)</p>	<p>Enable us to record and action your request about participation in the National Register. For more information on how to manage your participation in the National Register, refer to Part 4 - Your participation in the National Register.</p> <p>Record your nominated healthcare provider</p> <p>Determine whether you should not be sent any correspondence or invited to screen or sent a bowel test kit for a period of time or not at all</p> <p>Determine whether to include your screening test results in the National Register</p> <p>Defer or change a date you are due to undergo a screening test</p> <p>Enable us to use a pseudonym if requested</p> <p>Determine whether you have withdrawn a request made previously regarding your participation in the National Register</p> <p>Keep a database of records relating to cervical and bowel cancer screening and diagnoses</p>

Table 2 - Healthcare providers

Type of information collected	Data source	Purpose of collection, use and disclosure
Your name, address (including practice address), contact	Individual	<p>Verify your healthcare provider details to enable data matching</p> <p>Record you as an individual's nominated</p>

details and provider directory data *	Other healthcare providers Services Australia National Health Service Directory PRODA Endpoint Locator Service	healthcare provider, if applicable Communicate with you to advise if your patient may need to undergo cervical screening, or when follow up is required as a result of a cervical or bowel cancer screening test Provide advice if your patient has a positive result to enable referral or further examination and to support clinical decision making Communicate with states and territories when follow up is required in relation to your patient as a result of a cervical or bowel cancer screening test
Healthcare identifier (individual healthcare provider identifier or healthcare provider identifier for organisations)	Healthcare Identifiers Service Operator	Verify your healthcare provider details when you interact with the National Register

*this demographic information was initially migrated from state and territory cervical screening registers in order to set up the National Register.

Table 3 - Disclosure of information from the National Register

The National Register may disclose any relevant information it collects (as described in [Table 1](#) above), for a number of purposes and to various recipients under the NCSR Act. Below is a table setting out examples of to whom information may be disclosed and for what purpose.

Recipient	Purpose of disclosure and use by recipient
You, your personal representative	Provide you as a participant with invitations to undergo screening, reminder and follow-up services, access to your personal information, and cervical and bowel screening information. Enable you to manage your participation in the National Register. Assist you to receive appropriate follow up and access to health services in accordance with clinical guidelines
Your healthcare provider, including pathology providers and specialists	Provide your healthcare provider access to your clinical information relating to cervical or bowel cancer screening to enable clinical assessment, referral for further examination if you have a positive result, and support clinical management

	<p>Assist your healthcare provider to discuss screening with you and to manage your participation in screening</p> <p>Support decisions about clinical recommendations to the test referrer</p> <p>Provide a quality feedback loop for individual healthcare providers</p> <p>Support pathology providers with laboratory quality assurance activities (pathology providers only)</p>
<p>State and territory authorities or state and territory governments that are participating in the National Register</p>	<p>Provide the health department or agency in the state or territory where you reside (and move to if you relocate) access to your information relating to cervical or bowel cancer screening</p> <p>Share with states and territories to enable local program policy and service planning, monitoring and evaluation; and to implement strategies to increase screening participation, access to follow-up services, and maximise access of under-screened and never screened groups</p>
<p>Researchers</p>	<p>For research to support cervical and bowel cancer screening research, or other relevant research for public health purposes</p> <p>Research subject to meeting the requirements of the <i>National Cancer Screening Register Act 2016</i></p>
<p>AIHW</p>	<p>Enable screening program monitoring, analysis and evaluation</p>
<p>Governance committees</p>	<p>Enable screening program monitoring, analysis and evaluation (de-identified data only)</p>