



PRIVACY INFORMATION NOTICE

Use of personal information in the National Lung Cancer Screening Program

25 May 2025

This privacy information notice describes why, when, and how we collect, use and disclose your information to operate the National Cancer Screening Register (Register).

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

1. About the National Lung Cancer Screening Program

The National Lung Cancer Screening Program (Program) is an Australian Government screening program. The Program uses low-dose computed tomography (low-dose CT) scans to look for lung cancer in high-risk people without any symptoms. The Program aims to achieve better health outcomes for all Australians by detecting lung cancer early and reducing deaths from lung cancer. Early detection can lead to more effective treatment options and improved outcomes for patients. People aged between 50 to 70 years old with no signs or symptoms of lung cancer who smoke tobacco cigarettes/have a history of cigarette smoking may be able to participate in the Program.

2. About the National Cancer Screening Register (Register)

The Register is a national electronic infrastructure for the collection, storage, analysis and reporting of cancer screening program data for Australian Government screening programs. The Department is the custodian of the information in the Register. The Register is built and operated by Telstra Health, on behalf of the Department.



Australian Government

NATIONAL
LUNG CANCER
SCREENING
PROGRAM

3. Authorisation and privacy

We are authorised to collect, record, use and disclose certain information under the *National Cancer Screening Register Act 2016* (the Act) for the purposes of the Program. This Act regulates how the Register collects, records, uses, stores, and discloses information it holds about you and to whom it can be released.

We are also authorised to collect, use, disclose and store personal information in accordance with the *Privacy Act 1988* (Privacy Act) and the Australian Privacy Principles at Schedule 1 of the Privacy Act. Storage of personal information is managed in accordance with the *Archives Act 1983* and relevant Records Authorities and General Disposal Authorities.

Additionally, the Register Privacy Policy describes why, when, and how the Register and the Department collect, use, and disclose your information to operate the Register. It includes details about how the Register uses your information.

To find the Register Privacy Policy and to understand how the Register uses your information, please visit www.ncsr.gov.au/about-us/privacy-policy.html

4. Why your information is collected and how it will be used

We collect your personal information to identify you and support the functions of the Register. This supports the Program by providing you and your healthcare providers with the ability to access information about lung cancer screening and diagnoses.

The information collected helps the Register keep you (or your personal representative) up to date about your participation in the Program such as:

- reminding you when you are due to for screening
- sending follow-up reminders if you have not had a low-dose CT scan
- notifying you if you need to follow-up with your healthcare provider after a low-dose CT scan.

Information collected also includes findings related to lung cancer and additional actionable findings (also called incidental findings). Additional actionable findings are findings seen in the low-dose CT scan that do not relate to lung cancer but require you to follow up with your healthcare provider. This helps you to receive the best possible care.

We will communicate with your healthcare provider through correspondence and/or phone calls if you:

- are due for a low-dose CT scan
- need follow-up because of a low-dose CT scan result.

We share your information with healthcare providers so that your healthcare provider can view your results and let you know what to do next. This can help you to receive appropriate follow up and access to health services. Sharing your information assists your healthcare provider to discuss screening with you, manage your participation in screening and support decisions about clinical management recommendations.

Your radiologist will send the radiology report to your requesting healthcare provider to consider as part of your overall care in line with business-as-usual processes.

Healthcare providers, such as GPs, specialists, and radiologists, may disclose your information to other healthcare providers. This is to manage your lung cancer screening and any findings.

5. How information is collected and recorded on the Register

We will collect your personal information used in the Program. Your healthcare providers (such as your GP or specialist) will collect your information and share it to the Register. Your healthcare providers will manage any information they collect in line with their standard practice.

We will collect your information from a range of sources, including:

- your healthcare provider or specialist
- the radiology provider undertaking the low-dose CT scan
- the pathologist who examines biopsy tissue specimens (if applicable)
- Services Australia, the organisation who receives data once a Medicare Benefits Schedule claim is made
- hospitals, doctors or medical specialists whom you may be referred to
- your personal representative.

Information about how to opt-out of the Register is provided below.

6. Who your information is disclosed to

We may share your information with state or territory authorities or governments (such as health departments). This information may be used to support local program policy and service planning, monitoring and evaluation, and strategies to increase screening participation and access to follow-up services.

We may share your information with researchers to support lung cancer screening research or other relevant public health research, or research subject to meeting the requirements of the Act. We may disclose your information to researchers who are located overseas in de-identified form in line with the Register [Data Access and Release Policy](#).

We may share your information with the Australian Institute of Health and Welfare (AIHW) and governance committees. This enables screening program monitoring, analysis and evaluation.

We may also disclose your information in other circumstances as required under Australian law or court or tribunal orders, including to assist:

- a professional disciplinary authority, or enforcement body to undertake their functions or powers
- a court or tribunal proceeding
- a coronial inquiry

7. What information does the Register collect?

As part of the Program, a range of information is collected and stored in the Register, including:

- **Personal and demographic details such as:**
 - name
 - date of birth
 - contact details (such as your address, email address, and mobile phone number)
 - gender
 - Indigenous status
 - healthcare information, such as healthcare provider, healthcare identifier, and Department of Veteran's Affairs number
 - medical history, such as if you have a family history of lung cancer.
 - country of origin and/or cultural identity
 - preferred language
 - if you need an interpreter or support to manage medical conditions or disabilities to undertake a scan
 - details of your personal representative
 - date of death
- **Program participation information, such as:**
 - requests about your participation in the Register (including communications preferences), and the withdrawal of a previous request about your participation in the Register
 - Medicare information, such as your Medicare number, Medicare enrolment data (including demographic information), and Medicare claims information
 - when you had a low-dose CT scan (either screening or follow-up scan)
 - when you are due for a low-dose CT scan (either screening or follow-up scan)
 - the results (the report, not the scan image) of your low-dose CT scans and/or other tests undertaken as part of screening, and the diagnosis of lung cancer or precursor to lung cancer. The results of a low-dose CT scan may also include whether the low-dose CT has identified actionable additional findings that do not relate to lung cancer, but that have been detected as part of the low-dose CT scan
 - whether a healthcare provider has offered you help to stop smoking
 - any adverse events from screening tests.

8. What happens if your personal information is not collected

If we are not able to collect your information, we will be unable to send you or your healthcare provider any communication relating to the Program. This includes reminders that you are due for screening, that you are overdue for a low-dose CT scan, or if you need to act following your low-dose CT scan.

If you choose not to take part in the Register, you may still claim the MBS items for low-dose CT scan under the Program, however, you will not be recorded as a Program participant. Your healthcare provider will be responsible for your screening, including any reminders and follow-up after a scan.

9. Unsolicited information

In some cases, we may receive unsolicited information about you that is not relevant to the Register's functions or purposes. For example, a pathology lab might send detailed patient information along with the results of a lung biopsy. If the lab includes additional data, such as the patient's unrelated medical conditions or previous test results that were not specifically requested by the Register, this extra information would be considered unsolicited.

In these cases, the Register must determine whether it could have lawfully collected the information. If the Register could not lawfully collect the information, it will destroy the information or de-identify the information accordingly.

10. Opt-out information

You may request the Register to not contact you for a selected period of time, or not at all. We will still keep a record of your personal information and participation in the program.

You may also choose not to participate in the Register and opt-out of the Program. If you choose to opt-out, the Register will not collect any of your lung cancer screening results and will not send you any communications. Your historical clinical information will be made inaccessible from the date of your request. To understand what happens when you choose not to participate in the Register, please see [Information about opting out of the NCSR](#).

To opt out or manage your interaction with the Register, please refer to [Manage your participation](#).

You can choose to opt back in to the Register at any time.

11. How to make corrections to your information

You can update your details and manage your participation in the Program at any time by:

- using the Register's Participant Portal at: www.ncsr.gov.au/information-for-participants/participant-portal/
- calling the Register on 1800 627 701
- visiting your healthcare provider who can make the change on your behalf.

For further information on how to change your details or participation in the Program, please refer to Manage your participation at www.ncsr.gov.au/information-for-participants/manage-your-participation

If you need further assistance, the Department can help you request correction of your personal information, using the contact details in the Contact us section below.

12. How to access your information relating to the Program

You can access your information on the Register Participant Portal at: www.ncsr.gov.au/information-for-participants/participant-portal/

You can also request access to documents containing your own personal information by emailing the Department's Freedom of Information Unit at foi@health.gov.au More information about making freedom of information requests is available on our [FOI web page](#) or by contacting (02) 6289 1666.

The Department can help you obtain access to your personal information, using the contact details in the Contact us section below.

13. Complaints

If you have any concerns about your privacy or how your information is being used, you can contact:

- the Department using the contact details in the Contact us section below
- the Register using the details provided at: www.ncsr.gov.au/contact.html

If you wish to make a privacy complaint or are not satisfied with how the Department has handled your complaint, you can contact the Office of the Australian Information Commissioner at www.oaic.gov.au/contact-us

14. Queries about the Program and Register

The Department is responsible for the Program and the Register. If you have questions about the Program please contact us at: lungcancerscreening@health.gov.au

If you have questions about the Register, you can lodge an online enquiry with the Register at: www.ncsr.gov.au/contact.html#online-enquiry

15. Contact us

If you have questions about the privacy information notice, the Register Privacy Policy, or have any other queries, please contact the Department at:

Phone: (02) 6289 1555 or free call 1800 020 103

Online: [Visit Contact us | Department of Health, Disability and Ageing](#)

Email: enquiries@health.gov.au

Post: Department of Health, Disability and Ageing
GPO Box 9848
CANBERRA ACT 2601

For more information see the Register Privacy Policy at: www.ncsr.gov.au/about-us/privacy-policy.html



For information in your language go to **www.health.gov.au/nlcspp-translations** or call the Translating and Interpreting Service on **131 450**

العربية | Arabic

للإطلاع على معلومات بلغتك، يرجى زيارة www.health.gov.au/nlcsp-translations أو اتصل بخدمة الترجمة التحريرية والشفهية على الرقم 131 450.

Assyrian | ܐܬܘܪܝܝܬܐ

www.health.gov.au/ **nlcsp-translations**
 131 450

Chinese (Simplified) | 简体中文

如需以您的语言获取信息，请访问 www.health.gov.au/nlcsp-translations 或致电口笔译服务处 131 450。

Chinese (Traditional) | 繁體中文

如欲查閱此資訊的其他語言版本，請瀏覽
www.health.gov.au/nlcsp-translations 或致電
筆譯和口譯服務中心 (TIS National)：131 450。

Dari | دری

جهت کسب معلومات به لسان خودتان به www.health.gov.au/nlcs-p-translations مراجعه نموده یا به خدمات ترجمانی شفاهی و کتبی به نمرة 131 450 زنگ بزنید.

Greek | Ελληνικά

Για πληροφορίες στη γλώσσα σας μεταβείτε στη διεύθυνση **www.health.gov.au/nlcsp-translations** ή καλέστε την Υπηρεσία Μετάφρασης και Διερμηνείας στο **131 450**.

Hazaragi | هزارگی

بلده کسب مالومات د زیږون خود به www.health.gov.au/nlcs-p-translations کیدی د خدمات ترجمانی شفاهی و کتبی د شماره 131 450 زنگ دید.

Indonesian | Bahasa Indonesia

Untuk informasi dalam bahasa Anda, kunjungi **www.health.gov.au/nlcsp-translations** atau hubungi Layanan Penerjemahan dan Penjurubahasaan di **131 450**.

Italian | Italiano

Per informazioni nella tua lingua, consulta **www.health.gov.au/nlcsp-translations** o chiama il Servizio di traduzione e interpretariato al numero **131 450**.

Khmer | ភាសាខ្មែរ

សម្រាប់ព័ត៌មានជាភាសារបស់អ្នក សូមចូលទៅកាន់គេហទំព័រ
www.health.gov.au/nlcsp-translations ឬហៅទូរសព្ទទៅ
 សេវាកម្មប្រឹក្សាសាសន៍ស្មើ និងភាសាផ្ទាល់មាត់តាមលេខ **131 450**។

Korean | 한국어

여러분의 언어로 된 정보를 원하시면 www.health.gov.au/nlcsp-translations를 방문하거나 131 450번으로 통번역 서비스(Translating and Interpreting Service)에 전화하세요.

Macedonian | Македонски

За информации на вашиот јазик, одете на веб-страницата **www.health.gov.au/nlcsp-translations** или јавете се во Службата за писмено и усно преведување на **131 450**.

Nepali | नेपाली

तपाईंको भाषामा जानकारीको लागि www.health.gov.au/nlcsp-translations मा हेर्नुहोस् वा 131 450 मा अनुवाद तथा दोभाषे सेवालाई फोन गर्नुहोस्।

Farsi | فارسی

برای کسب اطلاعات به زبان خود به www.health.gov.au/nlcs-p-translations مراجعه کنید یا با خدمات ترجمه کتبی و شفاهی به شماره 131 450 تماس بگیرید.

Punjabi | ਪੰਜਾਬੀ

ਆਪਣੀ ਭਾਸ਼ਾ ਵਿੱਚ ਜਾਣਕਾਰੀ ਲਈ www.health.gov.au/nlcsp-translations 'ਤੇ ਜਾਓ ਜਾਂ 131 450 'ਤੇ ਅਨੁਵਾਦ ਅਤੇ ਦਫ਼ਤਰੀ ਸੇਵਾ ਨੂੰ ਫ਼ੋਨ ਕਰੋ।

Serbian | Српски

За информације на вашем језику, посетите **www.health.gov.au/nlcsp-translations** или позовите Службу за превођење и тумачење (Translating and Interpreting Service) на **131 450**.

Spanish | Español

Para obtener información en su idioma, visite **www.health.gov.au/nlcsp-translations** o llame al Servicio de Traducción e Interpretación al **131 450**.

Thai | ภาษาไทย

สำหรับข้อมูลในภาษาของคุณ ไปที่ www.health.gov.au/nlcsp-translations หรือโทรติดต่อบริการแปลและล่ามที่หมายเลข 131 450

Turkish | Türkçe

Kendi dilinizde bilgi almak için **www.health.gov.au/nlcsp-translations** adresine gidin veya **131 450** numaralı telefondan Yazılı ve Sözlü Tercüme Hizmetini arayın.

Vietnamese | Tiếng Việt

Để có thông tin bằng ngôn ngữ của quý vị, hãy truy cập **www.health.gov.au/nlcsp-translations** hoặc gọi đến Dịch vụ Biên Phiên dịch theo số **131 450**.