

Supporting health care providers in cancer screening: the role of the National Cancer Screening Register

A national digital infrastructure designed to support health care providers delivering bowel and cervical cancer screening

Registers are a key element of organised population-based cancer screening programs. Unlike cancer registers, which focus on collection and reporting of cancer diagnoses, cancer screening registers are digital platforms that support all aspects of the operations of screening programs by inviting, reminding and following up participants for screening. They generate comprehensive data to inform policy; monitor program performance, quality and safety; and support evaluation and improvements of cancer screening programs.

The Australian Government established and funded the National Cancer Screening Register (NCSR), a world-first interoperable digital platform, to initially support the National Cervical Screening Program (NCSP) and the National Bowel Cancer Screening Program (NBCSP). The key drivers for the NCSR included:

- addressing the need for a single contemporary, integrated and national digital platform, that would facilitate electronic data capture, thereby improving efficiency and reducing manual workflows;
- enabling the transition to a renewed NCSP based on a five-yearly primary human papillomavirus (HPV) cervical screening program and a two-yearly bowel cancer screening program; and
- supporting the participation in cancer screening by improving access to screening information and digital interaction with the programs for health care providers and participants.

The NCSR has been designed to accommodate future cancer screening programs as evidence of their effectiveness emerges. BreastScreen Australia data are not included in the NCSR because each state and territory is responsible for recording and managing client information and for operational activities such as issuing invitations and managing bookings. The Australian Government's commitment to addressing the impact of cancer has increased by 122%, growing from \$2.2 billion in 2013–14 to more than \$4.9 billion in 2020–21, with the NCSR supporting all operational aspects of cancer screening.¹

On 1 December 2017, the NCSP transitioned from a program based on Papanicolaou smear tests (Pap tests) every two years to primary HPV screening tests. The renewed NCSP now recommends women and people with a cervix to have a cervical screening test through their health care provider every five years starting at the age of 25 years and continuing until the age of 74 years.²

To support this significant change to the NCSP, it was a priority to consolidate the existing eight state

and territory cervical screening registers onto a new national screening register with functionality to support the renewed program. Legislation enabling the NCSR to operate as an opt-out register (the *National Cancer Screening Register Act 2016*) was passed in 2016 and permitted the NCSR to receive results for relevant cancer screening and diagnostic tests.

There were a number of key challenges to this transition, including migration of data from multiple registers and merging of 20% of records across jurisdictions, electronic integration of over 30 laboratories using electronic HL7 (Health Level Seven International) messaging in a standard format, and concurrent changes to national clinical guidelines. At the same time, screening laboratories and health care providers were adapting to significant workforce and operational changes required to transition to HPV primary screening.

The NBCSP commenced in 2006 with immunochemical faecal occult blood test (iFOBT) kits initially sent to eligible Australians at 55 and 65 years of age. The program was gradually expanded from 2008 and now offers screening every two years to people aged 50–74 years, with around 4 million Australians per year invited to screen. Age eligibility for cancer screening is determined on the basis of clinical program guidelines and evidence of reduced cancer-associated mortality from randomised trials as well as modelling of benefits versus harms and cost-effectiveness.^{2,3}

In November 2019, the previous register supporting the program based at Services Australia transitioned to the NCSR to create a single national record for participants of the NBCSP and the NCSP. The NCSR supports the NBCSP by distributing iFOBT kits to eligible people, reminding participants when they are overdue for screening and supporting follow-up activities conducted by state and territories. A description of age eligibility of the bowel and cervical screening programs, as well as cancer cases and incidence rates in the target age group are described in [Box 1](#).

Key functions and benefits of the NCSR

The NCSR is based on an interoperable digital platform that integrates with national infrastructure, in particular the Medicare database, Healthcare Identifiers Service, and myGov, as well as all major pathology laboratories that report cervical screening tests to the NCSR in near real time by standard electronic messaging (HL7). The Medicare database is

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doi:10.5694/mja2.52029

1 Bowel and cervical screening program age eligibility, cancer cases and incidence rate

Screening programs covered by the NCSR	Age-eligible cohort	Cancer cases and incidence rate in target age group
National Cervical Screening Program	Women and people with a cervix aged 25–74 years	<ul style="list-style-type: none"> • 851 new cases of cervical cancer reported in 2018 • Crude incidence rate of 10.9 per 100 000 population⁴
National Bowel Cancer Screening Program	People aged 50–74 years*	<ul style="list-style-type: none"> • It is estimated that there will be 7356 new cases of bowel cancer in 2023 • Estimated incidence rate of 103 per 100 000 population in 2023⁵

NCSR = National Cancer Screening Register. * Note that more intensive screening is recommended for people with a family history.⁶ ◆

the source of information on eligible participants, from which invitations to screen are issued.

The NCSR is a digital platform that collectively:

- links all the relevant population screening stakeholders — Commonwealth and state and territory governments, pathology, health care providers, and participants;
- connects and exchanges data in real time with the pathology sector, with clinical information loaded into each record, reducing reliance on general practice and other specialist reporting;
- complies with national and international health standards for messaging and uses unique individual health identifiers to match incoming results and information to participant records; and
- meets or exceeds the Australian Government’s security standards as a third party delivering an Australian Government national health solution.

The NCSR supports the end-to-end operations of the NBCSP and NCSP, and the key functions and benefits are described in [Box 2](#).

Digital channels: improving health care provider engagement in screening

New digital channels for health care providers are enabling end users to interact with the NCSR at a time convenient for them ([Box 3](#)). Health care providers access the Healthcare Provider Portal via PRODA (Provider Digital Access), which enables secure access for authorised users and delegated access for approved individuals (eg, practice nurses). Activity is monitored and audited by the NCSR on a regular basis.

The NCSR also integrates with clinical information systems to allow health care professionals to receive and report clinical data seamlessly from their existing clinical software within the patient record. A generic application programming interface based on Fast Healthcare Interoperability Resources (FHIR) has been enabled to allow approved clinical information systems vendors to apply for integration with the NCSR, and Best Practice, MedicalDirector and Communicare were the first vendors to integrate with the NCSR. Further integration is planned for other clinical information systems vendors as well

as specialist colposcopy and colonoscopy software products.

Over 16 000 health care providers have registered to access the portal, and over 2400 practices have integrated their clinical software as of May 2023 (NCSR, unpublished data). Over 80% of primary care practices in Australia use MedicalDirector and Best Practice, and most Aboriginal medical services use Communicare. Integration with the Communicare platform could help facilitate improved screening rates in Aboriginal and Torres Strait Islander communities, which is a high priority for the Australian Government.

The rate of adoption of integration with the NCSR shows high demand for secure, online channels, and has led to improvements in data quality and a significant reduction in paper forms, faxes, phone calls and manual processes. Over 85% of cervical screening histories are now accessed online, and faxed requests have dropped by 94% since the phased introduction of digital channels in 2020. Over 45% of replacement iFOBT orders are made digitally and are increasing (NCSR, unpublished data).

The NCSR self-service Participant Portal, accessed via myGov, enables participants to:

- update their personal details and nominate a health care provider;
- manage participation, including opting out of the program, correspondence, or deferral of the next screening;
- request an iFOBT kit; and
- view their next screening date.

As of May 2023, over 48 000 participants have linked their myGov account to the Participant Portal (NCSR, unpublished data), and this number is expected to rise over time as more participants adopt digital channels.

Digital access by health care providers to the NCSR will facilitate potential changes to target groups for screening by providing additional alerts and reminders for screening both higher risk and underscreened individuals through automated pathways based on up-to-date screening results. This will be particularly relevant in future as evidence accumulates for improved risk stratification or personalisation of screening enables better targeting of screening to higher risk individuals.

2 Functions and benefits of the National Cancer Screening Register (NCSR)

Functions	Benefits
A single screening record for each eligible participant in Australia	<ul style="list-style-type: none"> • It provides a single and more complete national record for cervical and bowel cancer screening for eligible people and participants. • It is accessible in real time and gives health care providers, pathologists and program staff the information they need to support people on their screening journey.
Integration with the MBS, Health Information Service and Provider Directory Service	<ul style="list-style-type: none"> • It keeps health care providers informed when their patients are overdue; it provides prompts for follow-up and facilitates clinical information capture. • It enables routine identification of under- and never-screened individuals by integration with the Medicare database; it assists in maximising cervical screening participation — cancer audits show more than 70% of people presenting with cervical cancer in Australia have never screened or are underscreened.⁷ This facilitates the government’s goal of eliminating cervical cancer by 2035. • It improves data completeness and provides screening stakeholders with information necessary for appropriate clinical decision making and to inform program policy (eg, Indigenous data capture increased from < 10% to > 70% following implementation of the NCSR). • It skips invitations for iFOBT if a participant has had a recent colonoscopy as determined by MBS item numbers.
Invitations and reminders to screen*	<ul style="list-style-type: none"> • It issues invitations and reminders to screen and drive participation (ie, “call–recall” function). • The NCSR routinely sends invitations for cervical screening to all eligible people, in addition to a health care provider recommendation; and iFOBT kits are primarily mailed to all eligible people for the NBCSP.
Follow-up function	<ul style="list-style-type: none"> • The NCSR acts as a safety net for cervical and bowel cancer screening programs to reduce the number of participants who are lost to follow-up. • It prompts health care providers to ensure participants complete actions according to clinical guidelines.
Reporting and data insights	<ul style="list-style-type: none"> • It extracts raw data and pre-configured reports developed for Commonwealth, state and territory program staff and the Australian Institute of Health and Welfare to: <ul style="list-style-type: none"> ▶ provide program monitoring and evaluation to drive responsive, evidence-based policy and program development; ▶ provide data to inform research, safety and quality including laboratory performance measures; ▶ inform service planning to ensure government resources and services are targeted toward improving the screening programs.
Clinically designed and nationally consistent algorithms are applied, using the participants’ past screening history and results	<ul style="list-style-type: none"> • It automates the screening pathway and facilitates appropriate reminders and follow-up. • It is adaptable for future implementation of risk stratification or personalised screening.
Multiple communication channels	<ul style="list-style-type: none"> • It enables screening program participants, health care providers, pathologists, follow-up teams, and Commonwealth, state and territory health departments to securely interact with the NCSR. • It facilitates communication between stakeholders and sharing of screening information to support the participants’ medical journey and ongoing monitoring of the screening programs.

iFOBT = immunochemical faecal occult blood test; MBS = Medicare Benefits Schedule; NBCSP = National Bowel Cancer Screening Program; NCSR = National Cervical Screening Program. * Approximately 150 000 letters distributed on average per week, including invitations, reminders and follow-up correspondence. Approximately 62 000 NBCSP iFOBT kits distributed on average per week (NCSR, unpublished data). ◆

Improving screening participation and population health outcomes

Recruitment of participants to cancer screening programs presently occurs in several ways:

- eligible people are sent invitations and iFOBT kits from the NCSR when they become newly eligible, as well as invitations and reminders when they become due and overdue for screening;
- health care providers may offer screening opportunistically or use their clinical information systems to send reminders when patients are due for screening — a patient’s full cervical or bowel screening history may not always be available; therefore, providers rely on the NCSR for the last test date and next screening action;
- participants may screen in response to media or other campaigns, which continue to be important for encouraging participation, and NCSR data are used to target and monitor their effectiveness.

Improving participation rates and population health outcomes is the key focus for cancer screening

programs. In 2020–2021, 6.1 million people aged 50–74 years were invited to participate in the NBCSP, and 2.49 million people returned a completed bowel screening test kit, setting the national participation rate at 40.9%.⁵ Modelling research shows that 84 000 lives could be saved by 2040 by increasing NBCSP participation to 60%.⁸

Over 4.2 million women and people with a cervix aged 25–74 years completed a cervical screening test, equating to a participation rate of 68% based on five years of available data (2018–2022).⁹ However, screening rates for Aboriginal and Torres Strait Islander peoples are lower than that of non-Indigenous people and cervical cancer incidence and mortality is more than two- to threefold higher.^{10,11} Improving data completion of Indigenous status and participation is a high priority for the NCSR and this has improved from 4.5% to 72% since the inception of the NCSR, largely due to inclusion of Medicare information.

Importantly, improving the involvement of health care providers in cancer screening programs can increase participation, as patients see their providers

3 Benefits to health care providers of new digital channels

The Healthcare Provider Portal* and integration with clinical information systems allow health professionals to:

- Access screening information, including previous screening dates and test results, for participants of both programs (including those who have been invited to participate, but have not done so yet)
- Lodge clinical forms and follow-up information relating to both programs electronically, in particular:
 - ▶ the general practitioner's assessment and colonoscopy/histopathology forms for the NBCSP;
 - ▶ the mandatory colposcopy form for the NCSP
- Issue NBCSP test kits directly to patients or have one sent to the address held by the NCSR
- Manage patient participation in the NCSP and NBCSP, including opting out and deferring their screening

NBCSP = National Bowel Cancer Screening Program; NCSP = National Cervical Screening Program; NCSR = National Cancer Screening Register. * For more information, visit <https://ncsr.gov.au/register-access>. ◆

as the most trusted source of health care advice.¹² The NCSR has worked to facilitate health care provider involvement by including digital channels that improve access to screening history and enable ordering of iFOBT kits directly via the portal or clinical information systems. This is of particular importance for underscreened populations, such as Aboriginal and Torres Strait Islander peoples, and aims to assist in reducing inequity. A new initiative based on a successful pilot project initiated and funded by the Department of Health and Aged Care and conducted by the Menzies School of Health Research allows health care providers to bulk order iFOBT kits for distribution in the clinic to maximise opportunities for screening. Participant details forms are completed directly through the clinical information systems or the Healthcare Provider Portal to ensure details are recorded in the NCSR.

Improved population health outcomes are facilitated by provision of NCSR data to approved stakeholders, including Commonwealth and state and territory health departments, the Australian Institute of Health and Welfare and authorised researchers.¹³ Quality assurance is enabled by providing screening laboratories with regular performance measures, and HPV positivity reports are published on the NCSR website to allow laboratories to benchmark their rates.

The NCSR is also collaborating with specialist colposcopists to provide reports for colposcopy quality assurance and with contracted agencies for program performance and quality and safety monitoring. Importantly, the NCSR is providing data to support the Australian Government's work to be the first country in the world to eliminate cervical cancer by 2035 and reduce preventable deaths from bowel cancer.

Conclusion

Australia's NCSR provides an interoperable digital infrastructure to fully support the cervical and bowel cancer screening programs from initial invitation and screening through to diagnosis and management, quality assurance and reporting, and is adaptable for future cancer screening programs. Health care provider engagement in screening is improved through better access to patient cancer screening records, as well as the ability to update records and order free iFOBT kits, facilitating better health outcomes through early detection and treatment of screen-detected abnormalities.

Acknowledgements: The National Cancer Screening Register (NCSR) is funded by the Australian Government and operated by Telstra Health. We acknowledge the long-standing contributions of the NCSR team, the Cancer Screening Programs Branch of the Department of Health and Aged Care, and state and territory cancer screening programs.

Open access: Open access publishing facilitated by The University of Melbourne, as part of the Wiley - The University of Melbourne agreement via the Council of Australian University Librarians.

Competing interests: We are employees of Telstra Health, which is contracted by the Australian Government Department of Health and Aged Care to build and operate the National Cancer Screening Register.

Provenance: Not commissioned; externally peer reviewed. ■

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