National Bowel Cancer Screening Program screening data 2018–2020; Quality Statement
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Identifying and definitional attributes

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Data quality

Data quality statement summary:

Summary of Key Issues

- National Bowel Cancer Screening Program (NBCSP) screening data are highly relevant for monitoring trends and outcomes from NBCSP screening participation.
- NBCSP data depend on the return of data forms from participants, general practitioners, colonoscopists and pathologists to the National Cancer Screening Register (NCSR).
- NBCSP data are now maintained in the National Cancer Screening Register (NCSR), which is operated by Telstra Health (TH) on behalf of the Australian Department of Health.
- Analysis by remoteness, socioeconomic status, Primary Health Network (PHN), Statistical Area Level 3 (SA3) and Statistical Area Level 2 (SA2) are based on Statistical Area 1 (SA1) or postcode of residential address of NBCSP invitees at the time of screening. Correspondences for these disaggregations may be unavoidably older than the year(s) of screening data being reported, potentially leading to inaccuracies.
- Aboriginal and Torres Strait Islander, language spoken at home and disability status are self-reported by participating individuals.
- Exclusion of people screened outside the NBCSP will result in an underestimation of bowel cancer population screening rates in the target ages.
- Data return for later stages in the NBCSP screening pathway (colonoscopy and pathology follow-up, as required) is not mandatory. This may result in under-reporting, and/or the inability to report on outcome data.

Description

The NBCSP is a national cancer screening program that started in 2006 and aims to reduce the morbidity and mortality from bowel cancer by using national invitation and screening analysis processes to actively recruit and screen the eligible target population for early detection or prevention of the disease. . A 'usual care' model is then used for follow-up functions for those with a positive (abnormal) screening result; that is, these people are encouraged to see their doctor to discuss the test result and seek further diagnostic testing (such as colonoscopy) as required. Data from these follow-up functions are returned to the NCSR via non-mandatory form return.

Program expansion to implement a biennial screening interval for those aged 50–74 started in January 2015 and roll-out (with all age groups included) was completed from 1 January 2019. Eligible Australians (Australian citizens or migrants in the Medicare enrolment file, or who are registered with a Department of Veterans' Affairs gold card) aged 50–74 will be invited to screen every 2 years.

Future biennial invitations are 2 years from:

- their previous invitation date (for those who did not participate the previous time) or
- their previous screening test date (for those who did participate the previous time).

NBCSP data depend on the return of data forms from participants, general practitioners, colonoscopists and pathologists to the NCSR. In November 2019, NBCSP data were transitioned from the NBCSP Register maintained by the Department of Human Services into the NCSR, which also houses National Cervical Screening Program data, and is currently maintained by Telstra Health (TH). This means that data are now available for download monthly.

The NBCSP is monitored annually by the AlHW. Results are compiled and reported at the national level by the AlHW in an annual NBCSP monitoring report. Activity is also reported quarterly.

Institutional environment:

The Australian Institute of Health and Welfare (AIHW) is a major national agency set up by the Australian Government under the <u>Australian Institute of Health and Welfare Act 1987</u> to provide reliable, regular and relevant information and statistics on Australia's health and welfare. It is an independent Commonwealth entity established in 1987, governed by a management <u>Board</u>, and accountable to the Australian Parliament through the Health Portfolio.

The AIHW aims to improve the health and wellbeing of Australians through better health and welfare information and statistics. It collects and reports information on a wide range of topics and issues, ranging from health and welfare expenditure, hospitals, disease and injury, and mental health, to ageing, homelessness, disability and child protection.

The Institute also plays a role in developing and maintaining national metadata standards. This work contributes to improving the quality and consistency of national health and welfare statistics. The Institute works closely with governments and non-government organisations to achieve greater adherence to these standards in administrative data collections to promote national consistency and comparability of data and reporting.

One of the main functions of the AIHW is to work with the states and territories to improve the quality of administrative data and, where possible, to compile national datasets based on data from each jurisdiction, to analyse these datasets and disseminate information and statistics.

The <u>Australian Institute of Health and Welfare Act 1987</u>, in conjunction with compliance to the <u>Privacy Act 1988</u>, ensures that the data collections managed by the AlHW are kept securely and under the strictest conditions with respect to privacy and confidentiality.

For further information see the AIHW website www.aihw.gov.au.

Previously, under agreement with the Department of Health and AlHW, the Department of Human Services supplied a de-identified snapshot of all NBCSP activity to the AlHW at 6-month intervals. In November 2019, NBCSP Register data were transitioned from the Department of Human Services to the NCSR that is currently managed by TH on behalf of the Department of Health. From 2020, the NCSR through TH provides a raw data extract of the NCSR data tables monthly that the AlHW can download for analysis. Data reported by the AlHW represent a 'snapshot' of the NCSR database at the time of extraction, and may not include retrospective updates made to data after the time of extraction.

Timeliness:

NBCSP data are available the following month, but many performance indicators require follow-up data to allow them to be calculated accurately. For example, reporting data for the year 2019 requires follow-up to the end of 2020 to allow at least one year for procedures to occur, such as a colonoscopy after a positive screening test.

The data discussed in this data quality statement cover the period January 2018–December 2020.

Accessibility:

NBCSP data are published annually in the NBCSP monitoring report available on the <u>AlHW website</u> where they can be downloaded without charge. Supplementary data tables presenting data that are more detailed accompany each report and these are also available on the <u>AlHW website</u> where they can be downloaded without charge.

Users can request data not available online or in reports via the Screening Analysis & Monitoring Unit of the AlHW on (02) 6244 1000 or via email to screening@aihw.gov.au. Requests that take longer than half an hour to compile are charged for on a cost-recovery basis.

General enquiries about AlHW publications can be made to the Strategic Communications and Stakeholder Engagement Unit on (02) 6244 1000 or via email to info@aihw.gov.au.

Interpretability:

Details of the current NBCSP performance indicators can be found at <u>Key</u> performance indicators for the <u>National Bowel Cancer Screening Program</u>.

While the concept of participation in the NBCSP is easy to interpret, the NBCSP screening pathway and other concepts and statistical calculations are more complex and may be confusing to some users. All concepts are explained within the body of the reports presenting these data, along with footnotes to provide further details and caveats. The appendixes provide additional detail on the data sources and classifications, and on the statistical methods used.

Relevance:

NBCSP screening data are highly relevant for monitoring trends and outcomes from NBCSP screening participation. The data are used for many purposes by policy-makers and researchers, but are supplied and analysed specifically to monitor and inform the NBCSP.

It is important to note that additional bowel cancer screening is undertaken outside of the NBCSP. Data on people screened outside the program are not routinely collected; therefore, the level of underestimation of overall bowel cancer screening in Australia is unknown.

Accuracy:

Self-reporting of Aboriginal and Torres Strait Islander, language spoken at home and disability status within the program means these data are only available for those who participate.

Socioeconomic status Index of Relative Socio-economic Disadvantage (IRSD) rankings are calculated by Postal Area (POA) using a population-based method at the Australia-wide level. These ranked socioeconomic status POAs are then allocated to their relevant jurisdiction, meaning quintiles should contain similar socioeconomic groups across jurisdictions.

Socioeconomic status IRSD rankings are only measured at the time of the Australian Census of Population and Housing and are not available for approximately 18 months from the Census date. Consequently, socioeconomic status for a geographical area may be up to 6 years old and not an accurate representation of the status of residents at the time the data are analysed. In addition, IRSD is a measure of the average disadvantage of households in an area and the level of disadvantage of an individual household may vary significantly from the average.

An Australian Bureau of Statistics POA to remoteness correspondence and a POA to socioeconomic status correspondence are used to allocate persons screened to remoteness and socioeconomic status areas based on their postcode of residence. The remoteness (and socioeconomic status) to POA correspondences are based on postal areas, boundaries and classifications as at the year of the last Australian census, which may have been up to 5 years earlier, and boundaries, socioeconomic status and remoteness regions may have changed over time, creating inaccuracies. New postal areas defined since the last Census will not have valid remoteness or socioeconomic status correspondence data available as they will not exist in earlier correspondences.

Correspondences that convert POAs and Statistical Area 1 geographies to PHN and Statistical Area geographies are also used. This may lead to some minor inaccuracies in results, as some postcodes cross PHN and Statistical Area geographies. This error tends to be largest in areas where the boundaries of the two geographies do not align, or when mapping from larger to smaller areas. Correspondences rated with a 'Poor' quality as determined by the Australian Bureau of Statistics are excluded from reporting. Records that cannot be converted by the correspondences are classified in an 'unknown' category.

NBCSP outcome data are via non-mandatory form return from GP visits, colonoscopies, histopathology, adverse events and surgical resection. The completeness of form return is unknown; therefore, there is an unknown amount of missing outcome data, which needs to be taken into consideration when reviewing NBCSP outcome analyses. Results of some analyses may be excluded where data are not considered complete enough to provide accurate information.

The data used in NBCSP monitoring reports allow for 6 months of follow-up time post-invitation. However, this may not be enough time for all people who had a positive screening result to have completed the screening pathway and had outcomes returned to the NCSR. This may also result in some under-reporting of outcome data.

Data return for later stages in the NBCSP screening pathway (colonoscopy and pathology follow-up as required) is not mandatory. This may result in underreporting, and/or the inability to report on outcome data.

NBCSP screening data are reported and published annually by the AlHW. However, the 2016 NBCSP monitoring report was the first to use the NBCSP performance indicators specified at: https://www.aihw.gov.au/reports/cancer-screening/key-performance-indicators-for-the-national-bowel/contents/table-of-contents. Therefore, results in reports from 2016 onwards cannot be compared with earlier reports. Instead, monitoring reports from 2016 onwards apply the new performance indicators to earlier years of data to provide data for earlier program years (and thus trends) using these indicators.

In future, the addition of extra screening ages and biennial rescreening are expected to affect results in most performance indicators, which will make reasons for changes in their overall trends difficult to interpret.

Coherence:

Source and reference attributes

Submitting organisation: Australian Institute of Health and Welfare

Relational attributes

Related metadata references:

Supersedes National Bowel Cancer Screening Program screening data 2017-

2019; Quality Statement

AlHW Data Quality Statements, Standard 01/12/2020

Has been superseded by National Bowel Cancer Screening Program screening

data 2019-2021; Quality Statement

AlHW Data Quality Statements, Superseded 28/04/2023