# National Bowel Cancer Screening Program screening data 2013–2015; 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 NBCSP Register.
- Analysis by remoteness, socioeconomic status, Primary Health Network (PHN) and Statistical Area 3 (SA3) are based on postcode or Statistical Area 1 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 and disability status are selfreported by participating individuals.
- Exclusion of people screened outside the NBCSP will result in an underestimation of 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, or suppression of incomplete outcome data.
- Data may be suppressed or excluded for confidentiality and reliability reasons (for example, incompleteness of data, if the denominator is less than 100, or the rate could not be sensibly estimated).

#### **Description**

The NBCSP is managed by the Australian Government Department of Health in partnership with state and territory governments. The NBCSP started in 2006 and uses national invitation and screening analysis processes. 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 national NBCSP Register via non-mandatory form return.

Currently people that are registered as Australian citizens or migrants in the Medicare enrolment file, or are registered with a Department of Veterans' Affairs gold card receive a screening invitation at, or around, their 50<sup>th</sup>, 55<sup>th</sup>, 60<sup>th</sup> and 65<sup>th</sup> birthdays. From January 2015, program expansion to implement a biennial screening interval for those aged 50–74 will start. It is due to be completed by 2020.

NBCSP data depend on the return of data forms from participants, general practitioners, colonoscopists and pathologists to the NBCSP Register. The register is maintained by the Department of Human Services (formerly Medicare Australia). Data from the register are provided to the Australian Institute of Health and Welfare (AlHW) 6-monthly as de-identified unit record data.

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.

#### Institutional environment:

The 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 corporate Commonwealth entity established in 1987, governed by a management Board, 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 AIHW 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 AIHW 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.

The <u>Australian Institute of Health and Welfare Act 1987</u>, in conjunction with compliance to the <u>Privacy Act 1988</u>(Cwlth), 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, <a href="http://www.aihw.gov.au">http://www.aihw.gov.au</a>.

Under agreement with the Department of Health and AlHW, the Department of Human Services supply a de-identified snapshot of all NBCSP activity to the AlHW at 6-month intervals. The AlHW has been receiving these data, for reporting purposes, since 2006.

Timeliness:

The data discussed in this data quality statement cover the period January 2013–December 2015, and will first be made publically available in July 2016.

Therefore, the performance indicators included in this report use the latest practical data available.

Accessibility:

The NBCSP annual monitoring reports, and any supplementary data, are available via the AlHW website where they can be downloaded free of charge. Users can request data not available online or in reports via the Cancer and Screening Unit of the AlHW on (02) 6244 1000 or via email to <a href="mailto:screening@aihw.gov.au">screening@aihw.gov.au</a>. 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 Digital and Media Communications Unit on (02) 6244 1000 or via email to <a href="mailto:info@aihw.gov.au">info@aihw.gov.au</a>.

Interpretability:

This latest NBCSP monitoring report for 2016 is the first to present data based on the new NBCSP performance indicators. Details of these can be found at <a href="http://www.aihw.gov.au/publication-detail/?id=60129548923">http://www.aihw.gov.au/publication-detail/?id=60129548923</a>.

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. 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.

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.

#### **Accuracy:**

Self-reporting of Aboriginal and Torres Strait Islander, language spoken at home and disability status within the program means these data are dependent on accurate, and complete, information.

Socioeconomic status Index of Relative Socio-economic Disadvantage (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 out of date and not an accurate representation of the status of residents at the time the data is analysed.

An Australian Bureau of Statistics postal area (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. POAs are defined to match Australia Post postcodes as closely as possible, but for various reasons, they do not match identically. Socioeconomic status is calculated using a population-based method at the Australia-wide level.

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 match the old postal areas.

Correspondences that convert POAs and Statistical Area 1 geographies to Primary Health Network and Statistical Area 3 geographies are also used. Records that cannot be converted by the correspondences are classified in an 'unknown' category.

NBCSP outcome data is via non-mandatory form return from GP visits, colonoscopies, histopathology, adverse events and surgical resection. The level of form return may be 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 allows 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 NBCSP Register. This may also result in some underreporting of outcome data.

Some data cells have been suppressed for confidentiality and reliability reasons (for example, if the denominator is less than 100, or the rate could not be sensibly estimated).

Coherence:

NBCSP screening data are reported and published annually by the AlHW. However, the 2016 NBCSP monitoring report is the first to use the new NBCSP performance indicators. Therefore, results in this report cannot be compared with earlier reports. Instead, the 2016 monitoring report applies the new performance indicators to earlier years of data to provide trends using the new indicators.

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

#### Source and reference attributes

**Submitting organisation:** Australian Institute of Health and Welfare

Relational attributes

Related metadata references:

Supersedes <u>National Bowel Cancer Screening Program screening data: 2013–14;</u>
<u>Quality Statement</u>

AlHW Data Quality Statements, Superseded 20/07/2016

Has been superseded by <u>National Bowel Cancer Screening Program screening data 2014–2016; Quality Statement</u>

AlHW Data Quality Statements, Superseded 29/01/2019