National Bowel Cancer Screening Program screening data: July 2008–June 2011

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# National Bowel Cancer Screening Program screening data: July 2008–June 2011

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| Identifying and definitional attributes | |
| Metadata item type: | Data Quality Statement |
| Synonymous names: | NBCSP DQS |
| METEOR identifier: | 500507 |
| Registration status: | [AIHW Data Quality Statements](https://meteor.aihw.gov.au/RegistrationAuthority/5), Standard 14/03/2013 |

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| Data quality | |
| Data quality statement summary: | **Summary of Key Issues**   * The National Bowel Cancer Screening Program (NBCSP) is a joint program of the Australian Government Department of Health and Ageing and state and territory governments. The NBCSP is monitored annually by the AIHW. Results are compiled and reported at the national level by the AIHW in an annual NBCSP monitoring report. * 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 Medicare Australia. Data from the register are provided to the AIHW six monthly as de-identified unit record data. * Analysis of remoteness and socioeconomic status are based on postcode of residential address of NBCSP invitees at the time of screening. Concordances for these disaggregations may be unavoidably older than the year(s) of screening data being reported, leading to inaccuracies. * Aboriginal and Torres Strait Islander, language and disability status are self-reported 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 (GP, colonoscopy and pathology follow-up, as required) is not mandatory. Further, not all people who received a positive (abnormal) screening result may have had time to complete follow-up steps at the time of reporting. These factors may result in under-reporting of outcome data. * Data may be suppressed for confidentiality and reliability reasons (for example, if the denominator is less than 1,000, the numerator is less than 5, or the rate could not be sensibly estimated).   **Description**  The NBCSP is a joint program of the Australian Government Department of Health and Ageing and 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 those Australians registered at Medicare Australia or the Department of Veterans’ Affairs receive a screening invitation at, or around, their 50th, 55th and 65th birthdays. From 2013 the program will also include people aged 60, and from 2015 those aged 70. The program will be further expanded in 2017–18 with a phased roll out of biennial screening for those aged 50–74.  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 Medicare Australia. Data from the register are provided to the AIHW six monthly as de-identified unit record data.  The NBCSP is monitored annually by the AIHW. Results are compiled and reported at the national level by the AIHW in an annual NBCSP monitoring report. |
| Institutional environment: | The Australian Institute of Health and Welfare (AIHW) is a major national agency set up by the Australian Government under the Australian Institute of Health and Welfare Act 1987 to provide reliable, regular and relevant information and statistics on Australia's health and welfare. It is an independent statutory authority established in 1987, governed by a management Board, and accountable to the Australian Parliament through the Health and Ageing 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.  The Australian Institute of Health and Welfare Act 1987, in conjunction with compliance to the Privacy Act 1988 (Cth), ensures that the data collections managed by the AIHW 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.  The AIHW has been receiving NBCSP screening data since 2006. |
| Timeliness: | The data discussed in this data quality statement are for the period July 2008–June 2011.  A snapshot of all NBCSP activity is made available to the AIHW regularly at 6-month intervals for analysis. However, as there is a time lag between issuing invitations and confirmed diagnosis of bowel cancer, the monitoring reports are based on outcomes of a cohort of people sent invitations in a given period—this is usually cut off about 6 months prior to the date of the data supply to allow for sufficient follow-up data for analysis.  Therefore, the NBCSP data held at the AIHW at any given time is approximately 6 months behind the current date. |
| Accessibility: | The NBCSP annual monitoring reports, and any supplementary data, are available via the AIHW 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 AIHW 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 AIHW publications can be made to the Communications, Media and Marketing Unit on (02) 6244 1032 or via email to <info@aihw.gov.au>.  General enquiries about AIHW publications can be made to the Communications, Media and Marketing Unit on (02) 6244 1032 or via email to info@aihw.gov.au. |
| Interpretability: | 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 appendices 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 census and are not available for approximately 18 months from the census date. Consequently, socioeconomic status for a geographic 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 concordance and a POA to socioeconomic status concordance are used to allocate persons screened to remoteness and socioeconomic status categories based on their postcode of residence. Postal areas 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 concordances 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 concordance data available as they will not match the old postal areas.  NBCSP outcome data is via non-mandatory form return from GP visits, colonoscopy, histopathology, adverse events and surgical resection. The level 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.  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 Register. This may also result in some under-reporting of outcome data.  Some data cells have been suppressed for confidentiality and reliability reasons (for example, if the denominator is less than 1,000, the numerator is less than 5, or the rate could not be sensibly estimated). |
| Coherence: | NBCSP screening data are reported and published annually by the AIHW. Changes in reporting practices over time are clearly noted throughout the monitoring reports. In future, the addition of extra screening ages and biennial rescreening are expected to affect results in most areas of the screening pathway. |
| Data products | |
| Implementation start date: | 25/10/2012 |
| Source and reference attributes | |
| Submitting organisation: | Australian Institute of Health and Welfare |