National Bowel Cancer Screening Program NBEDS 2023–24

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Identifying and definitional attributes

Metadata item type:	Data Set Specification
METEOR identifier:	756105
Registration status:	<u>Health,</u> Standard 09/12/2022
DSS type:	Data Set Specification (DSS)
Scope:	The National **Bowel Cancer** Screening Program national best endeavours data set (NBCSP NBEDS) comprises a set of standardised data definitions used for monitoring the National Bowel Cancer Screening Program. This NBEDS includes information on people who have or will be participating in the National Bowel **Cancer Screening** Program.

This metadata set is not mandated for collection, i.e. it reflects best practice when collecting data in relation to bowel screening rather than a nationally mandated set of data that must be provided.

It is intended to be used by the National Cancer Screening Register. It can also be used by a wider range of health and health-related professionals who collect and/or use the data in relation to the National Bowel Cancer Screening Program.

It provides concise, unambiguous definitions for items related to the Program and aims to ensure the standardised methodology of data collection.

The data set covers data in the following areas:

- Demographic data of participants
- Bowel cancer screening tests (such as the **faecal occult blood test**)
- Bowel cancer diagnostic assessments (such as colonoscopy examinations and histopathological analyses on colorectal cancers and colorectal polyps).

General Practitioner consultations are not included at this stage. |

Collection and usage attributes

Statistical unit:	People who have or will be participating in bowel cancer screening programs.
Collection methods:	Screening data on participants' interaction with the National Bowel Cancer Screening Program are collected from participants themselves, pathologists who analyse participants' samples for the faecal occult blood test (FOBT), general practitioners (GPs) with whom participants consult for bowel cancer screening related reasons, colonoscopists who conduct colonoscopies on the participants, histopathologists who analyse specimens of abnormal growths such as suspected colorectal cancer or colorectal polyps from the participants. Data from all these sources are then forwarded to the National Bowel Cancer Screening Program Register.

The Register also collects data on its routine operation.

The Register provides data to the Australian Institute of Health and Welfare for data analyses and reporting purposes. |
| **Implementation start date:** | 01/07/2023 |
| **Implementation end date:** | 30/06/2024 |

Comments: *Glossary items*

Glossary terms that are relevant to this data set are included here:

[Adoption](#)

[Adverse event](#)

[Bowel cancer](#)

[Cancer diagnostic assessment](#)

[Cancer screening](#)

[Colonoscopy](#)

[Colorectal cancer clinico-pathological stage](#)

[Colorectal polyps](#)

[Disability](#)

[Disease screening](#)

[Faecal occult blood test (FOBT)](#)

[Family](#)

[Geographic indicator](#)

[Hospital-in-the-home care](#)

[Record linkage](#)

[Separation](#)

[Urban Centre and Locality](#)

Source and reference attributes

Submitting organisation: Australian Institute of Health and Welfare

Relational attributes

Related metadata references: Supersedes [National Bowel Cancer Screening Program NBEDS 2022–23](#)
[Health](#), Superseded 09/12/2022

See also [National Bowel Cancer Screening Program performance indicators 2019–](#)
[Health](#), Standard 06/09/2018

Metadata items in this Data Set Specification

Seq No.	Metadata item	Obligation	Max occurs
1	[Person—person identifier, X[X(19)]](#)	Mandatory	1
2	[Correspondence—correspondence identifier, N[N(8)]](#)	Mandatory	99

DSS specific information:

People can have multiple interactions with the National Bowel Cancer Screening Program (NBCSP) system and will have a different correspondence number for each interaction. For example, a person will have a correspondence identifier for a screening invitation, a faecal occult blood test (FOBT), a general practitioner consultation and a colonoscopy.

Seq No.	Metadata item	Obligation	Max occurs
3	Person—given name, text X[X(39)]	Mandatory	1
4	Person—given name sequence number, code N[N]	Mandatory	1
5	Person—family name, text X[X(39)]	Mandatory	1
6	Person—sex, code X	Mandatory	1
7	Person—date of birth, DDMMYYYY	Mandatory	1
8	Person—age, total years N[NN]	Mandatory	1
9	Person—Indigenous status, code N	Mandatory	1
10	Person—main language other than English spoken at home, code (ASCL 2016) N[NNN]	Mandatory	1
11	Person—disability status, yes/no/not stated/inadequately described code N	Mandatory	1
12	Person—Australian state/territory identifier, code N	Mandatory	1

DSS specific information:

This is the person's state or territory of usual residence.

Seq No.	Metadata item	Obligation	Max occurs
13	Address—Australian postcode, code (Postcode datafile) NNNN	Mandatory	1
14	Person—geographic remoteness, classification (ASGS-RA) N	Mandatory	1
15	Person—area of usual residence, statistical area level 1 (SA1) code (ASGS Edition 3) N(11)	Mandatory	1

DSS specific information:

To accurately report SEIFA information, sufficient geographic information needs to be reported. For the NBCSP, the data element Person—area of usual residence, statistical area level 1 (SA1) code (ASGS Edition 3) N(11) needs to be provided.

Seq No.	Metadata item	Obligation	Max occurs
16	Person—disease screening program invitation date, DDMMYYYY	Mandatory	1
17	Person—disease screening invitation round count, total number N[N]	Mandatory	1
18	Person—first disease screening program participation indicator, yes/no code N	Mandatory	1
19	Person—participation in previous biennial screening program indicator, yes/no code N	Conditional	1

Conditional obligation:

Reporting of this data element is conditional upon answering 'No' to the Person—first disease screening program participation indicator, yes/no code N data element.

Seq No.	Metadata item	Obligation	Max occurs
20	Person—opted off from a disease screening program indicator, yes/no code N	Mandatory	1

DSS specific information:

Invitees who do not wish to participate in the National Bowel Cancer Screening Program now or in the future may opt off the Program. Invitees will not be contacted again. Invitees may elect to opt back on at a later date.

Seq No.	Metadata item	Obligation	Max occurs
21	Person—reason for opting off a disease screening program, code N	Conditional	1

Conditional obligation:

Reporting of this data element is conditional upon answering 'Yes' to the Person—opted off from a disease screening program indicator, yes/no code N data element.

22	Person—opted off from a disease screening program date, DDMMYYYY	Conditional	1

Conditional obligation:

Reporting of this data element is conditional upon answering 'Yes' to the Person—opted off from a disease screening program indicator, yes/no code N data element.

23	Person—suspended participation from a disease screening program indicator, yes/no code N	Mandatory	1

DSS specific information:

Invitees who would like to participate in the National Bowel Cancer Screening Program but are unable to do so at this time. Invitees will be contacted once the nominated suspension period has elapsed.

24	Person—reason for suspending disease screening participation, code N	Conditional	1

Conditional obligation:

Reporting of this data element is conditional upon answering 'Yes' to the Person—suspended participation from a disease screening program indicator, yes/no code N data element.

25	Person—suspended participation from a disease screening program date, DDMMYYYY	Conditional	1

Conditional obligation:

Reporting of this data element is conditional upon answering 'Yes' to the Person—suspended participation from a disease screening program indicator, yes/no code N data element.

26	Person—cancer screening test indicator, yes/no code N	Mandatory	1
27	Bowel cancer screening test cluster	Conditional	1

Conditional obligation:

Reporting of the data elements in this cluster is conditional upon answering 'Yes' to the Person—cancer screening test indicator, yes/no code N data element.

1	Person—cancer screening test type, bowel cancer code N	Mandatory	1
2	Person—disease screening test completion status, bowel screening code N	Mandatory	1
3	Person—disease screening test analysis date, DDMMYYYY	Mandatory	1
4	Person—disease screening test results sent date, DDMMYYYY	Mandatory	1

Seq No.	Metadata item	Obligation	Max occurs
5	Person—cancer screening test result, bowel cancer code N[A]	Mandatory	1

DSS specific information:

A **faecal occult blood test** (FOBT) screening test is:

- positive if blood was detected in either sample
- negative if blood was not detected in either sample
- inconclusive if only one sample was taken and it was negative
- no result if screening test could not be analysed.

Other screening tests, when they become available, may have different indications for positive results. However, a positive result with any screening test is one that means further investigations are required.

Participants with a positive result are encouraged to visit their primary health care professional to follow up this finding. Those with an inconclusive result are requested to complete another FOBT kit, while those with a negative result are reminded that it is recommended they rescreen every two years.

At this stage, the screening pathway does not account for false negatives or positives.

Seq No.	Metadata item	Obligation	Max occurs
28	Person—cancer diagnostic assessment indicator, yes/no code N	Mandatory	1

DSS specific information:

Participants with a positive faecal occult blood test (FOBT) result, indicating blood in their bowel motion, are advised to consult their primary health care practitioner to discuss further testing.

Seq No.	Metadata item	Obligation	Max occurs
29	Bowel cancer diagnostic assessment cluster	Conditional	1

Conditional obligation:

Reporting of the data elements in this cluster is conditional upon answering 'Yes' to the Person—cancer diagnostic assessment indicator, yes/no code N data element.

Seq No.	Metadata item	Obligation	Max occurs
1	Patient—cancer diagnostic assessment date, DDMMYYYY	Mandatory	1
2	Patient—cancer diagnostic assessment type, bowel cancer code N	Mandatory	1
3	Establishment—Australian state/territory identifier, code N	Mandatory	1

DSS specific information:

This is the state or territory in which a bowel cancer diagnostic assessment occurs. This can be different to the person's state or territory of usual residence, e.g. a person living in Queanbeyan (in NSW) may undergo a diagnostic assessment in Canberra, i.e. in the ACT.

Seq No.	Metadata item	Obligation	Max occurs
4	Patient—colonoscope withdrawal time, total minutes NNN	Conditional	1

Conditional obligation:

Reporting of this data element is conditional upon answering 'Colonoscopy' to the Person—cancer diagnostic assessment type, bowel cancer code N data element.

Seq No.	Metadata item	Obligation	Max occurs
5	Patient—colonoscope depth, anatomical site within the bowel code XX[XX]	Conditional	1

Conditional obligation:

Reporting of this data element is conditional upon answering 'Colonoscopy' to the Person—cancer diagnostic assessment type, bowel cancer code N data element.

6	Patient—election status, code N	Mandatory	1
7	Patient—sedation received indicator, yes/no code N	Mandatory	1

DSS specific information:

The level of sedation used should comply with Australian and New Zealand College of Anaesthetists (ANZCA) standards (ANZCA 2014). The level of sedation used should generally be related to the risk of complications for each individual patient as documented in the pre-procedure patient assessment. Further, deep sedation and general anaesthesia may only be used in the presence of an anaesthetist or other appropriately trained and credentialed medical specialist within his/her scope of practice. Non anaesthetist medical staff require adequate training in the safe and correct usage of sedation equipment and drugs, and in the management and monitoring of sedated patients in accordance with the guidelines.

Reference:

ANZCA 2014. Guidelines on Sedation and/or Analgesia for Diagnostic and Interventional Medical, Dental or Surgical Procedures. Viewed 14 October 2021, https://www.anzca.edu.au/resources/professional-documents/guidelines/ps09-guidelines-sedation-analgesia-for-diagnostic

8	Patient—sedation type, code N	Conditional	1

Conditional obligation:

Reporting of this data element is conditional upon answering 'Yes' to the Patient—sedation received indicator, yes/no code N data element.

9	Patient—type of health professional who administers sedation, bowel cancer diagnostic assessment code N	Conditional	1

Conditional obligation:

Reporting of this data element is conditional upon answering 'Yes' to the Patient—sedation received indicator, yes/no code N data element.

10	Patient—colorectal polyps found in colon indicator, yes/no code N	Mandatory	1
11	Patient—number of colorectal polyps found, N[NN]	Conditional	1

Conditional obligation:

Reporting of this data element is conditional upon answering 'Yes' to the Patient—colorectal polyps found in colon indicator, yes/no code N data element.

DSS specific information:

There could be multiple polyps listed if multiple polyps are found during an assessment.

Seq No.	Metadata item	Obligation	Max occurs
12	Patient—colorectal polyps greater than or equal to 10 mm indicator, Yes/no code N	Conditional	5

Conditional obligation:

Reporting of this data element is conditional upon answering 'Yes' to the Patient—colorectal polyps found in colon indicator, yes/no code N data element.

DSS specific information:

There could be multiple polyps listed if multiple polyps are found during an assessment.

Seq No.	Metadata item	Obligation	Max occurs
13	Patient—anatomical site of colorectal polyps, code XX[XX]	Conditional	5

Conditional obligation:

Reporting of this data element is conditional upon answering 'Yes' to the Patient—colorectal polyps found in colon indicator, yes/no code N data element.

DSS specific information:

There could be multiple polyps listed if multiple polyps are found during an assessment.

Seq No.	Metadata item	Obligation	Max occurs
14	Patient—colorectal polyp type, code N[N]	Conditional	5

Conditional obligation:

Reporting of this data element is conditional upon answering 'Yes' to the Patient—colorectal polyps found in colon indicator, yes/no code N data element.

DSS specific information:

There could be multiple polyps listed if multiple polyps are found during an assessment.

Seq No.	Metadata item	Obligation	Max occurs
15	Patient—grade of colorectal polyps found, code N	Conditional	5

Conditional obligation:

Reporting of this data element is conditional upon answering 'Yes' to the Person—colorectal polyps found in colon, yes/no code N data element.

DSS specific information:

There could be multiple polyps listed if multiple polyps are found during an assessment.

Seq No.	Metadata item	Obligation	Max occurs
16	Patient—adverse event indicator, yes/no code N	Mandatory	1

DSS specific information:

There is the risk of an adverse event occurring during a cancer diagnostic assessment. Monitoring of adverse events through the NBCSP is important to ensure participant safety in the Program.

Seq No.	Metadata item	Obligation	Max occurs
17	Patient—type of adverse event, bowel cancer diagnostic assessment adverse event code N[N]	Conditional	1

Conditional obligation:

Reporting of this data element is conditional upon answering 'Yes' to the Person—adverse event indicator, yes/no code N data element.

Seq No.	Metadata item	Obligation	Max occurs
18	Patient—cancer status, code N	Mandatory	1

DSS specific information:

Codes 8 and 9 are not used in the Bowel cancer diagnostic assessment cluster.

Seq No.	Metadata item	Obligation	Max occurs
30	Bowel cancer diagnosed cluster	Conditional	1

Conditional obligation:

Reporting of the data elements in this cluster is conditional upon people who have or will be participating in bowel cancer screening programs answering 'Yes' to the Patient—cancer status, code N data element.

Seq No.	Metadata item	Obligation	Max occurs
1	Person with cancer—primary site of cancer, topography code (ICD-O-3) ANN.N	Mandatory	1
2	Patient—diagnosis date of cancer, DDMMYYYY	Mandatory	1
3	Cancer staging—cancer staging scheme source, code N[N]	Mandatory	1

DSS specific information:

The data element is used to derive a value describing the patient's **colorectal cancer clinico-pathological stage**.

Seq No.	Metadata item	Obligation	Max occurs
4	Cancer staging—staging basis of cancer, code A	Mandatory	1

DSS specific information:

The data element is used to derive a value describing the patient's **colorectal cancer clinico-pathological stage**.

Seq No.	Metadata item	Obligation	Max occurs
5	Person with cancer—extent of primary cancer, TNM stage (UICC TNM Classification of Malignant Tumours, 8th ed) code X[XX]	Mandatory	1

DSS specific information:

The data element is used to derive a value describing the patient's **colorectal cancer clinico-pathological stage**.

Seq No.	Metadata item	Obligation	Max occurs
6	Episode of admitted patient care—admission date, DDMMYYYY	Conditional	1

Conditional obligation:

Conditional on the person being admitted for care as a result of their bowel cancer diagnosis

Seq No.	Metadata item	Obligation	Max occurs
31	[Person—date of death, DDMMYYYY](#)	Conditional	1

Conditional obligation:

Only to be answered if the person has died.

Seq No.	Metadata item	Obligation	Max occurs
32	[Person—underlying cause of death, code (ICD-10 2016 version) ANN{.N}](#)	Conditional	1

Conditional obligation:

Only to be answered if the person has died.