



NB-IRDT

New Brunswick Institute for
Research, Data and Training

Breast Cancer Screening Database

**Reference Guide
For Years 1996-2014**

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Breast Cancer Screening Database Reference Guide

HOW TO OBTAIN MORE INFORMATION

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- visit our website at go.unb.ca/fr-nbirdt
- email us at nb-irdt@unb.ca
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ABOUT THIS GUIDE

This reference guide is intended for users of the Breast Cancer Screening Database. This guide provides an overview of the data, the general methodology used in its creation and important technical information. It contains operational procedures as well as table and field descriptions. The development of this document is an ongoing process that will be updated with changes that occur in the Breast Cancer Screening Database.

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OVERVIEW

Breast cancer is the most frequently diagnosed cancer and the second leading cause of cancer death among women in New Brunswick. The New Brunswick breast cancer screening (NBBCS) program was established in 1995. The program provides eligible women access to mammography screening in accordance to Canadian guidelines. The goal is to detect breast cancer at an early stage and reduce deaths due to breast cancer. The program provides bilateral, two-view screening mammography biennially to eligible women throughout the province. The target population is defined as asymptomatic women between the ages of 50 to 69 years without prior diagnosis of breast cancer. Women aged 40-49 or greater than 69 require a physician or nurse practitioner's referral to the program.

The Breast cancer screening database is a provincial database which contains data from the New Brunswick Breast Cancer Screening Program. The New Brunswick Institute for Research Data and Training (NB-IRDT) holds an anonymized, linkable version of this data which provides project specific datasets with further scrambled identifiers to researchers.

More information on the screening program may be found at:

<http://www2.gnb.ca/content/gnb/en/departments/health/NewBrunswickCancerNetwork/content/NewBrunswickBreastCancerScreeningProgram.html>

Data Range

1996-2014 (Fiscal Years)

Data Source

New Brunswick Department of Health

How to cite this guide – paper reference guide

New Brunswick Institute for Data, Research and Training. (2017). *Breast Cancer Screening Database Reference Guide for Year 1996-2014*. Fredericton, NB: New Brunswick Institute for Research, Data and Training.

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<http://www.unb.ca/fredericton/arts/nbirdt/resources/pdfs/nb-breast-cancer-screening-refguide.pdf>

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Acknowledgements

The Breast Cancer Screening Database is used with permission of the New Brunswick Department of Health.

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ABOUT THIS PRODUCT

Purpose of the product

The purpose of the Breast cancer screening database reference guide is to provide information on the linkable New Brunswick breast screening data to researchers for public health and other research as well as for the development of population estimates and projections.

Content

This version of the Breast Cancer Screening Database contains four (4) groups of data elements:

| Group | Description |
|--------------|--------------------|
| 1 | Client Registry |
| 2 | Inquiry Log |
| 3 | Program Screens |
| 4 | Cancers from BCSS |

Each group includes the name, type (character or numeric), length, description, and count of non-missing values of the data elements.

General methodology

The Breast Cancer Screening database contains anonymized socio-demographic information, risk factors, screening events, screening results, follow-up results, and, where applicable, diagnoses of screen and non-screen-detected breast cancers of participants of the screening program.

This data from the Department of Health is stored securely by the NBIRD for authorized access to researchers.

Reference Date

1996-2014 (Fiscal Years)

TECHNICAL SPECIFICATIONS

Record layouts and data descriptions

1. Client Registry

Contains client information recorded when client entered the screening program

| Variable Name | Type | Description |
|---------------------------|------|----------------------------------|
| IRID | C | Scrambled client ID |
| Region of Birth | N | Client's region of birth |
| Parity | N | Number of full-term pregnancies |
| Age at First Birth | N | Age at first full-term pregnancy |

The type 'N' refers to numeric values while 'C' refers to both alphabetic and numeric characters.

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IRID (Interim Record ID)

Interim record identifier.

Region of Birth

Client's region of birth

Parity

Number of full-term pregnancies including still births

Age at First Birth

Age in years at first full term pregnancy: Age at which the woman first completed a pregnancy beyond the period of viability (generally taken as 20 weeks gestation). This is the age at which the woman delivered her first infant, whether live or stillborn. The first induced or spontaneous abortion is not considered as this event occurred prior to 20 weeks of gestation.

| Number | Meaning |
|---------------|----------------|
| 9 - 55 | Valid number |
| -8 | N/A |
| -9 | Missing |

Changes

May 13, 2002 Name changed from Age at First Birth

May 13, 2002 Values changed to numeric age instead of range. In effect with data from 1998 onwards.

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2. Inquiry Log

| Variable Name | Type | Description |
|----------------------------------------|-------------|-------------------------------------------|
| Date of Program Screen | D | Date of program screen |
| Family History | C | First degree family history of cancer |
| Menopausal Status | C | Menopausal status |
| Hormone Therapy | C | Hormone replacement therapy use |
| Months since External Mammogram | C | Number of months since external mammogram |

The type 'D' refers to date, 'N' refers to numeric values while 'C' refers to both alphabetic and numeric characters.

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Date of Program Screen

Dt_of_prog_screen: Month and year that the screening event took place.

Family History

Family_history: First degree family history of breast cancer. A family history of breast cancer limited to first degree (mother, sister, daughter, father, brother, son) blood relative.

| Code | Description |
|-------------|------------------------------------|
| 00 | No |
| 01 | Yes, age not specified |
| 02 | Yes, diagnosed at <50 years of age |
| 03 | Yes, diagnosed at ≥50 years of age |
| -9 | Missing |

Changes

May 13, 2002 Name changed from Family History of Breast Cancer

May 13, 2002 Added categories 02 – Yes, diagnosed at <50 years of age, and 03 – Yes, diagnosed at ≥50 years of age. In effect with data from 1998.

Menopausal Status

Menopsl_status: A client is classified as pre-menopausal if a menstrual period has occurred within the previous year, or a hysterectomy has been performed with one or both ovaries left in place and the current age is less than 50 years.

A client is classified as post-menopausal if no menstrual period has occurred in the previous year, or a hysterectomy has been performed with one or both ovaries left in place and the current age is ≥50, or both ovaries have been removed. If a client does not know if her ovaries were in place, it is assumed that they are.

| Code | Value |
|-------------|--------------|
| 01 | Pre |
| 02 | Post |
| -9 | Missing |

Hormone Therapy

Hormone_therapy: The client's history of hormone replacement therapy usage.

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| Code | Description |
|-------------|-------------------------------------------------|
| 01 | Ever user (not current) |
| 02 | Never user |
| 03 | Current use |
| 04 | Not current user (previous HRT history unknown) |
| -9 | Missing |

Changes

May 13, 2002 New category 03 – Current user added. In effect with data from 1998
 May 8, 2007 New category 04 – Not current user (previous HRT history unknown). In effect with data from 2002 onwards.

Months since External Mammogram

Number of months between current screen (first screen or re-screen) and the last mammogram external to the screening program.

| Code | Description |
|-------------|---------------------------------|
| 01 | Never |
| 02 | <12 months |
| 03 | 12-23 months |
| 04 | 24-35 months |
| 05 | 36-47 months |
| 06 | 48-59 months |
| 07 | 60+ months |
| 08 | Ever (number of months unknown) |
| -9 | Missing |

Changes

May 13, 2002 New category 03 – Current user added. In effect with data from 1998 onwards
 Altered/added categories
 May 8, 2007 New category 04 – Not current user (previous HRT history unknown) added. In effect with data from 2002 onwards.

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3. Program Screens

Records screen event information when a client visits the screening program

| Variable Name | Type | Description |
|-----------------------------|------|-------------------------------------------------------|
| Date of Program Screen | D | Date of program screen |
| Screening Method | C | Screening method |
| Screening Result | C | Screening result |
| Follow-Up Status | C | Referred for follow-up status |
| Tissue Density | C | Fibroglandular tissue density |
| Date of Final Diagnosis | D | Date of final diagnosis for screen-detected anomalies |
| Final Diagnosis | C | Final diagnosis for screen detected anomalies |
| Date Notified | D | Date notified of screen result |
| Mammography Exam Image Type | C | Mammography exam image type |
| Mammography Read Type ID | C | Mammography read type |
| Screen Site Type | C | Screening site type |
| Facility ID | | Screening facility ID |

The type 'N' refers to numeric values, 'D' refers to date, while 'C' refers to both alphabetic and numeric characters

Date of Program Screen

Dt_of_pro_screen: Date on which screening event took place.

Screening Method

Screen_method: Type of screening method performed during the screening visit.

| Code | Description |
|------|-------------|
| 01 | Mammogram |

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| | |
|-----------|------------------------------------------------|
| 02 | Clinical breast examination |
| 03 | Both mammogram and clinical breast examination |

Screening Result

The result of the screening visit – a summary of the findings from the screening mammography.

| Code | Description |
|-----------|--------------------------------------------|
| 00 | Client not referred |
| 20 | Radiologist referred left breast |
| 02 | Radiologist referred right breast |
| 22 | Radiologist referred left and right breast |
| 99 | Either breast referred by radiologist |

Follow-Up Status

Fol_up_status: Referred for follow-up status. This field is used to determine if diagnostic follow-up is necessary and if the diagnostic follow-up is complete.

| Code | Description |
|-----------|-----------------------------------------------------------------|
| 01 | Not referred |
| 02 | Completed diagnostic follow-up |
| 03 | Still in the process of diagnostic follow-up |
| 04 | Lost to diagnostic follow-up |
| -9 | Missing (follow-up complete but staging data not available yet) |

Tissue Density

Fibroglandular tissue density: Proportion of dense glandular tissue relative to fat tissue in the breast, as determined by the radiologist. If there is a double reading, the density is taken from the first reading if both are normal. Or if one is abnormal, the density is taken from the abnormal reading.

| Code | Description |
|-----------|-------------|
| 01 | < 50 % |
| 02 | ≥ 50 % |
| 03 | < 25 % |

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|-----------|------------|
| 04 | 25 - <50 % |
| 05 | 50 - <75 % |
| 06 | ≥75% |
| 07 | <75% |
| -9 | Missing |

Changes

May 13, 2002 New categories: 03 to 07 added. In effect with data from 1998 onwards.

May 13, 2002 Definition altered: Added “as determined by the radiologist”. In effect with data from 1998 onwards.

Date of Final Diagnosis

Date of the first core or open biopsy to diagnose cancer, or the first conclusive open biopsy following an inconclusive or incorrect core. The date of final diagnosis for benign cases is the date of the last test before a return to screening or before the recommendation for repeat diagnostic imaging.

Changes

May 13, 2002 Definition added. In effect with data from 1998 onwards.

Mar 21, 2007 Definition added. In effect with data 2002 onward.

Apr 20, 2010 Definition added. In effect with data 2004 onward.

Final Diagnosis

Final diagnosis at the end of screening episode.

| Code | Description |
|-------------|---------------------------------------------------------------------------------------------------------------------------------------|
| 01 | Breast cancer |
| 02 | No breast cancer |
| 03 | LCIS alone |
| 04 | ADH alone |
| 05 | Other high risk lesions (e.g. papilloma, radial scar, phyllodes tumour) |
| 06 | Diagnosed high risk lesion - type unknown (Use if province does not record if AND, papilloma, radial scar, phyllodes tumour, etc.) |
| -8 | N/A (not referred) |

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-9

Missing (in process or lost to follow-up)

Changes

May 13, 2002 Definition wording altered.

May 13, 2002 Category altered, added word: "breast". In effect with data from 1998 onwards.

Nov 18, 2009 New categories added: 04 – ADH alone, 05 – Other high risk lesions. In effect with data 2004 onwards.

May 5, 2010 Category added: 06 – Diagnosed high risk lesion - type unknown is used if province does not record if AND, papilloma, radial scar, phyllodes tumour, etc.

Date Notified

Date result letter was generated notifying client of screen result. Some programs hold the letter for a certain length of time in order to allow time for a similar letter to reach the family physician first.

Mammography Exam Image Type

Type of screening mammography image used. Equipment was used to do the exam.

| Code | Description |
|------|-------------|
| 01 | Film screen |
| 02 | Digital DR |
| 03 | Digital CR |
| -9 | Missing |

Changes

May 8, 2007 Variable added. In effect with data from 2002 onwards.

Mammography Read Type ID

Type of screening mammography read. (How was the image read?)

| Code | Description |
|------|--------------------|
| 01 | Film (with CAD) |
| 02 | Film (without CAD) |
| 03 | Digital (with CAD) |

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| | |
|-----------|-----------------------|
| 04 | Digital (without CAD) |
| 05 | Film (CAD unknown) |
| 06 | Digital (CAD unknown) |
| 9 | Missing |

Changes

May 8, 2007 Variable added. In effect with data from 2002 onwards.

Screen Site Type

Type of screening site. Fixed site or mobile.

| Code | Description |
|-------------|--------------------|
| 01 | Fixed site |
| 02 | Mobile site |
| 9 | Missing |

Changes

Nov 6, 2007 Variable added, in effect with data from 2002 onwards.

Facility ID

Number which identifies facility where screening took place.

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4. Cancers from BCSS

| Variable Name | Type | Description |
|------------------------|------|------------------------------|
| Date of program screen | D | Date of program screen |
| Date of Diagnosis | D | Date of definitive diagnosis |
| Detection Type | C | Detection type code |
| Measurement Type | C | Tumour measurement type |

The type 'N' refers to numeric values, 'D' refers to date, while 'C' refers to both alphabetic and numeric characters.

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Date of program screen

Date on which screening event took place.

Date of Diagnosis

Procedure Date of Definitive Diagnosis: Procedure date of earliest definite core or open biopsy that confirmed breast cancer diagnosis, or the first conclusive open biopsy following an inconclusive or incorrect core.

10000101 – Missing

Changes

May 13, 2002 Name changed from 'Date of Diagnosis'

May 13, 2002 Definition altered, in effect with data from 1998 onwards.

Apr 20, 2010 Definition added, in effect with data 2004 onward.

Detection Type

Detection type code.

| Code | Description |
|-------------|--------------------|
| 00 | Screen-detected |
| 01 | Interval |
| 02 | Non-compliance |

Interval cancer: Any post screen detected breast cancer diagnosed within the program-specific recommended screening interval (exactly 12 or 24 months) after a normal or benign screening episode.

Non-compliance cancer: A post screen detected breast cancer diagnosed beyond the program-specific recommended screening interval (exactly 12 or 24 months) after a normal screening episode or refusal of follow-up for an abnormal screen.

If no specific recommended screening interval exists, then biennial is assumed.

Changes

May 13, 2002 Definition modified

May 8, 2007 Definition modified

Nov 6, 2008 Definition modified

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May 5, 2010 Definition modified, in effect with data 2004 onwards.

Measurement Type

Measurement type code: Type of measurement used to determine the tumour size (best method). Includes post neo-adjuvant treatment staging if no pre-treatment information is available.

| Code | Description |
|-------------|----------------------|
| 01 | Pathologic |
| 02 | Radiologic |
| 03 | Clinical |
| 04 | Combination of above |
| -8 | N/A |
| -9 | Missing |

Changes

May 5, 2010 Definition modified, in effect with data 2004 onwards.

May 8, 2007 Category added: 04 – Combination of above. In effect with data from 2002 onwards