Options to enhance BreastScreen Australia data collection and reporting to support potential future risk-based breast cancer screening

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Roadmap for Optimising Screening in Australia — Breast

Investigating risk-based breast cancer screening in Australia

www.cancer.org.au/go/rosabreast

Report: **Enhanced BreastScreen data collection and reporting** (December 2021)

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Background

- BreastScreen Australia services routinely collect **high quality data** for every participant at every screening episode
- Increased interest in future risk-based breast cancer screening in Australia
- Data enhancements required to prepare for risk-based screening and to monitor screening outcomes according to risk factors

Image source: BreastScreen NSW

Research question and methodology

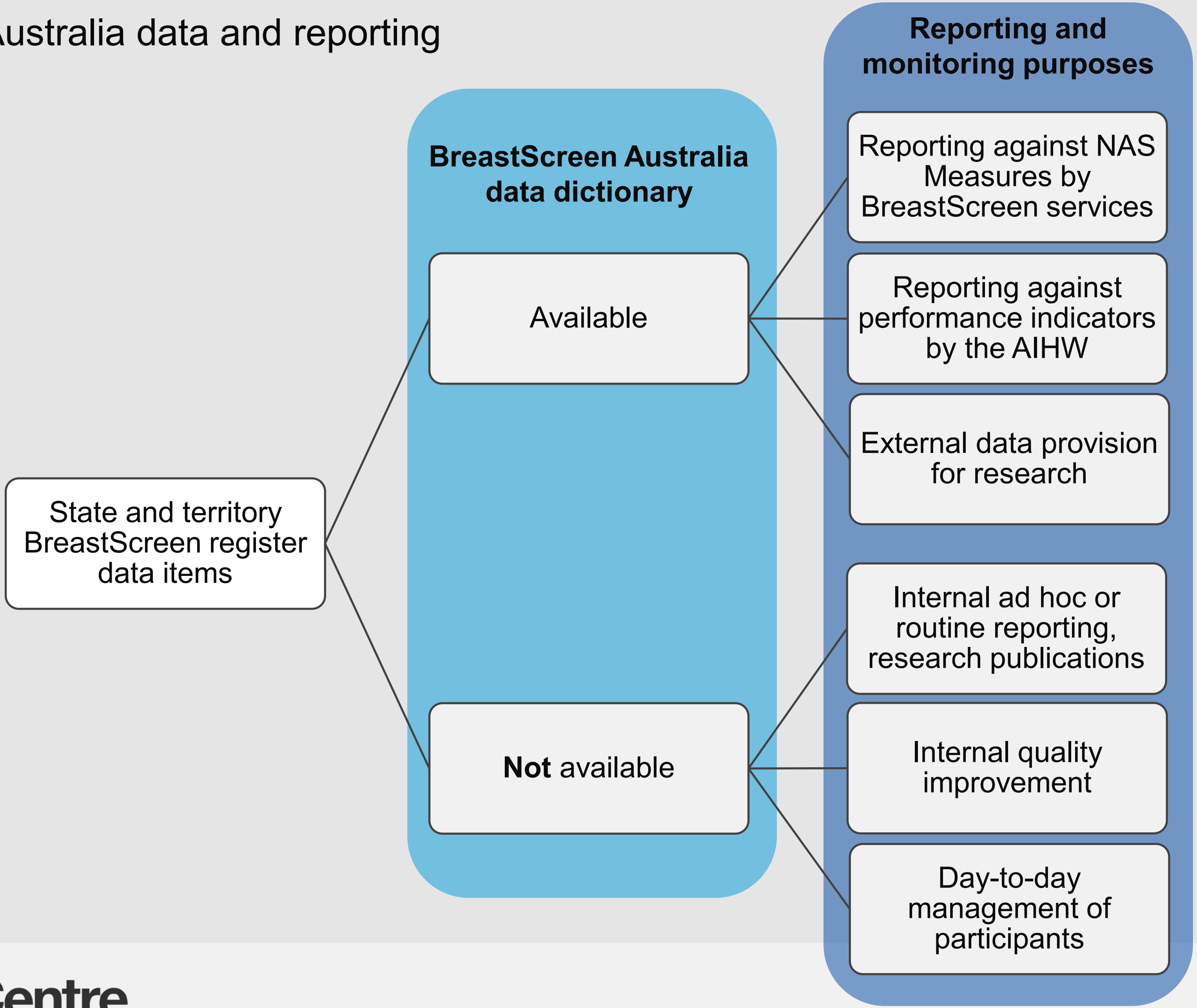
What BreastScreen data enhancements could support potential future risk-based screening protocols?

Mixed methods approach (desktop review, literature review, survey):

1. BreastScreen and AIHW data structures and reporting
2. Data items potentially relevant to risk-based screening
3. Current/historical data collection and reporting for data items
4. Priority options to enhance data
5. Requirements to support potential data enhancements

BreastScreen and AIHW data structures and reporting

BreastScreen Australia data and reporting



State and territory BreastScreen register data items

BreastScreen Australia data dictionary

Available

Not available

Reporting and monitoring purposes

Reporting against NAS Measures by BreastScreen services

Reporting against performance indicators by the AIHW

External data provision for research

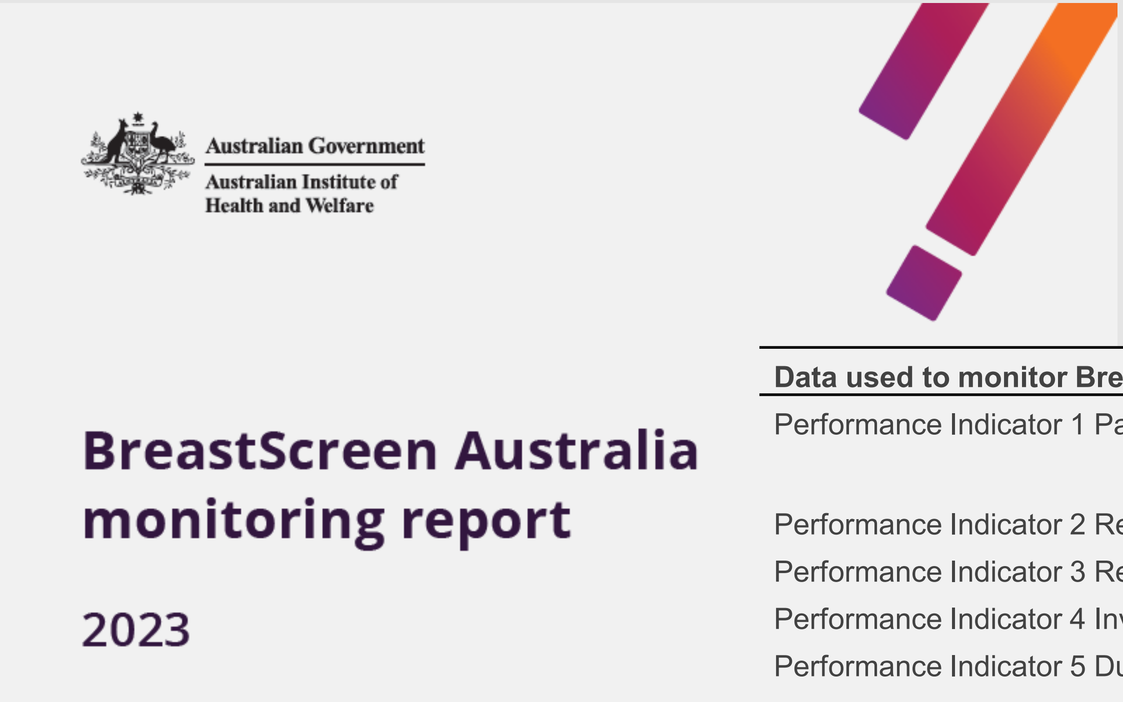
Internal ad hoc or routine reporting, research publications

Internal quality improvement

Day-to-day management of participants

BreastScreen and AIHW data structures and reporting

AIHW: Data custodians of BreastScreen data



Australian Government
Australian Institute of Health and Welfare

BreastScreen Australia monitoring report

2023

Data used to monitor BreastScreen Australia	Data source
Performance Indicator 1 Participation	State and territory BreastScreen register data (unit record); ABS population data
Performance Indicator 2 Rescreening	State and territory BreastScreen register data (aggregate)
Performance Indicator 3 Recall to assessment	State and territory BreastScreen register data (unit record)
Performance Indicator 4 Invasive breast cancer detection	State and territory BreastScreen register data (unit record)
Performance Indicator 5 Ductal carcinoma in situ detection	State and territory BreastScreen register data (unit record)
Performance Indicator 6a Interval cancers	State and territory BreastScreen register data (aggregate)
Performance Indicator 6b Program sensitivity	State and territory BreastScreen register data (aggregate)
Performance Indicator 7a Invasive breast cancer incidence	AIHW Australian Cancer Database; ABS population data
Performance Indicator 7b Ductal carcinoma in situ incidence	AIHW Australian Cancer Database; ABS population data
Performance Indicator 8 Mortality	AIHW National Mortality Database; ABS population data

Data items potentially relevant to risk-based screening

- Biennial screening (women 40y+, targeted 50-74y) or annual screening (additional criteria)

- Annual screening criteria varies across States and Territories:
  - Previous LCIS, ADH, AKH
  - Personal history of breast cancer
  - Strong family history of breast cancer
  - Ovarian cancer
  - Genetic factors

  → Data may be available for participants according to these factors

- Other data items relevant to risk-based screening? *Desktop review*

Item
Items related to breast cancer risk in the BSA data dictionary and AIHW reports
Breast cancer risk factors in validated breast cancer risk assessment tools
Items for sub-populations with disparate participation and cancer outcomes

Data items potentially relevant to risk-based screening

Risk factors reported and included in risk assessment tools

- Age
- Personal history of breast cancer or DCIS
- Personal history of benign breast disease
- Family history of breast cancer or DCIS
- Symptom status
- Annual screening
- Breast density
- Genetic factors e.g., BRCA 1/2 status
- Reproductive risk factors
- Menopausal hormone therapy use
- Risk estimated by validated assessment tool

Populations with disparate participation and outcomes

- Indigenous status
- Socioeconomic status
- Remoteness
- Culture and language diversity

Current/historical data collection and reporting for data items

Literature scoping review (2020-2021)

- Availability of national-level BreastScreen performance outcomes reported according to data items of interest for risk based-screening
- Literature and reports published Jan 2008-Oct 2020

Survey of BreastScreen program managers (2021)

- Representatives from each state and territory BreastScreen surveyed on current (to 2021) and historical collection of data items

AIHW desk review (2021)

- Data quality and completeness

Current/historical data collection and reporting for data items: **Literature scoping review**

BreastScreen Australia national data by factors of interest for risk-based screening: routinely reported data and opportunities for enhancement

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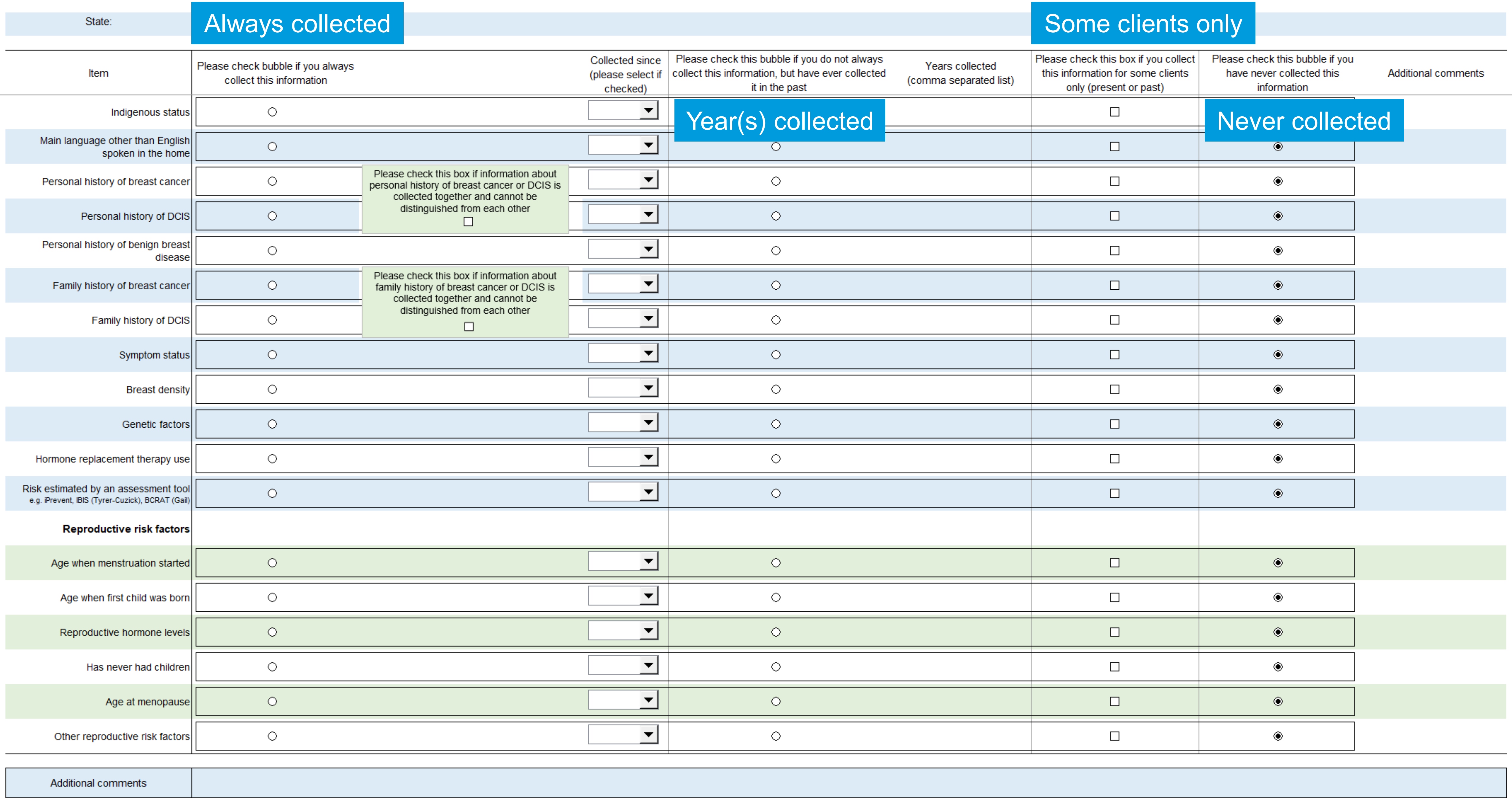
Findings:

- 4 government reports and 2 articles with data available
- Performance indicators (participation, rescreening, recall to assessment, program sensitivity, and detection rates: invasive cancers, DCIS, interval cancers) reported annually by **age**
- Participation reported annually by **Indigenous status, socioeconomic status, remoteness, CALD**
- Cancer detection data from 2001-2012 for some items: **Indigenous status, remoteness, CALD, personal and family history of breast cancer**

Current/historical data collection and reporting for data items: **Survey BreastScreen program managers**



Always collected

Some clients only

Year(s) collected

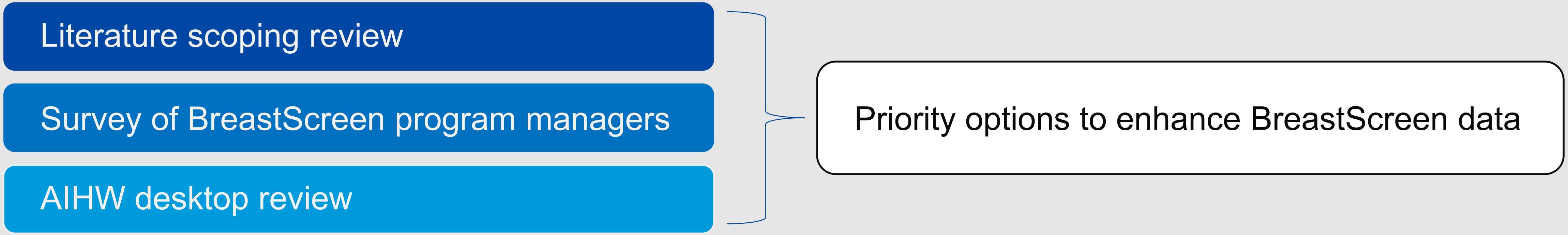
Never collected

State:

Item	Please check bubble if you always collect this information	Collected since (please select if checked)	Please check this bubble if you do not always collect this information, but have ever collected it in the past	Years collected (comma separated list)	Please check this box if you collect this information for some clients only (present or past)	Please check this bubble if you have never collected this information	Additional comments
Indigenous status	○				☐		
Main language other than English spoken in the home	○		○		☐	●	
Personal history of breast cancer	○ Please check this box if information about personal history of breast cancer or DCIS is collected together and cannot be distinguished from each other ☐		○		☐	●	
Personal history of DCIS	○		○		☐	●	
Personal history of benign breast disease	○		○		☐	●	
Family history of breast cancer	○ Please check this box if information about family history of breast cancer or DCIS is collected together and cannot be distinguished from each other ☐		○		☐	●	
Family history of DCIS	○		○		☐	●	
Symptom status	○		○		☐	●	
Breast density	○		○		☐	●	
Genetic factors	○		○		☐	●	
Hormone replacement therapy use	○		○		☐	●	
Risk estimated by an assessment tool e.g. iPrevent, IBIS (Tyrer-Cuzick), BCRAT (Gail)	○		○		☐	●	
Reproductive risk factors							
Age when menstruation started	○		○		☐	●	
Age when first child was born	○		○		☐	●	
Reproductive hormone levels	○		○		☐	●	
Has never had children	○		○		☐	●	
Age at menopause	○		○		☐	●	
Other reproductive risk factors	○		○		☐	●	

Additional comments

Priority options to enhance data



Literature scoping review

Survey of BreastScreen program managers

AIHW desktop review

Priority options to enhance BreastScreen data

Priority options to enhance data

Tier 1 options: Items collected by **all** BreastScreen services and **reported to AIHW**

- Age
- Indigenous status
- Socioeconomic status
- Remoteness
- Information reflecting clients who are culturally and linguistically diverse
- Personal history of breast cancer or DCIS
- Family history of breast cancer or DCIS
- Symptom status

AIHW analysis of existing data

Priority options to enhance data

Tier 1 options: Items collected by **all** BreastScreen services and **reported to AIHW**

- Age
- Indigenous status
- Socioeconomic status
- Remoteness
- Information reflecting clients who are culturally and linguistically diverse
- Personal history of breast cancer or DCIS
- Family history of breast cancer or DCIS
- Symptom status

AIHW analysis of existing data

Tier 2 options: Items collected by **all** BreastScreen services but **not yet reported to AIHW** or at a national level

- Annual screening
- Menopausal hormone therapy use

Extra data provided to AIHW

Priority options to enhance data

Tier 1 options: Items collected by **all** BreastScreen services and **reported to AIHW**

- Age
- Indigenous status
- Socioeconomic status
- Remoteness
- Information reflecting clients who are culturally and linguistically diverse
- Personal history of breast cancer or DCIS
- Family history of breast cancer or DCIS
- Symptom status

AIHW analysis of existing data

Tier 2 options: Items collected by **all** BreastScreen services but **not yet reported to AIHW** or at a national level

- Annual screening
- Menopausal hormone therapy use

Extra data provided to AIHW

Tier 3 options: Items collected by **some** BreastScreen services and **reported ad hoc**

- Personal history of benign breast disease
- Breast density
- Genetic factors e.g., BRCA 1/2 status
- Reproductive risk factors
- Risk estimated by validated assessment tool

Coordinated national collection

Requirements to support potential data enhancements

Establish change management protocol

National committees
Stakeholders
Decision-making bodies & mechanisms

Governance framework

BreastScreen Australia Data Dictionary

Specify data items and reporting

Details of data collection
Intended analyses

Data use and reporting

Requirements to support potential data enhancements

Resourcing and planning considerations

- Personnel
- Lead time
- Systems and processes
- Funding

Summary

To enhance BreastScreen data collection and reporting to support potential future risk-based screening protocols:

- Additional analysis of data items already collected
- Extra data provision and analyses of items not yet provided to the AIHW
- Coordinated collection of items collected by some services

To support this:

- Change management protocol
- Specify data items and reporting
- Resourcing and planning considerations

Website: www.cancer.org.au/go/rosabreast
Join mailing list: rosabreast@nswcc.org.au

Thank you

AIHW

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