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

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BreastScreen Australia is Australia's national government-funded population breast cancer screening program, provided by state and territory jurisdictional BreastScreen services. It offers biennial mammographic screening targeted to women aged 50-74 years (available from age 40, including age 75+), aiming to reduce breast cancer mortality through earlier detection, before symptoms arise.[1] Phased in from 1991 and fully implemented by 1995, the program is estimated to reduce mortality in screening participants by 41-52%[2,3] and to significantly reduce the intensity of required treatment.[4]

Age is the predominant risk factor for BreastScreen eligibility and targeting. While breast cancer risk increases with age, the target age range for screening (extended from 50-69 to 50-74 in 2013) is considered to confer the best balance of benefits and harms. For other breast cancer risk factors, annual mammography is offered to selected BreastScreen clients according to their history of benign breast disease, personal or family history of breast or ovarian cancer, or genetic factors known to increase breast cancer risk, with policies and practices varying between jurisdictions.[5-10]

Outside BreastScreen, some risk-based surveillance services are available to women without breast symptoms. For example, Royal Australian College of General Practitioners guidelines recommend supplemental ultrasound or magnetic resonance imaging (MRI) for asymptomatic women with a risk

Abstract

Objective: There is growing interest in more risk-based approaches to breast cancer screening in Australia. This would require more detailed reporting of BreastScreen data for factors of interest in the assessment and monitoring of risk-based screening. This review assesses the current and potential availability and reporting of BreastScreen data for this purpose.

Methods: We systematically searched governmental BreastScreen reports and peer-reviewed literature to assess current and potential availability of outcomes for predetermined factors including breast cancer risk factors and factors important for implementing, monitoring or evaluating risk-based screening. Outcomes evaluated were BreastScreen Performance Indicators routinely included in BreastScreen Australia monitoring reports, and key tumour characteristics.

Results: All outcomes were reported annually by age group, except for tumour hormone receptor status, nodal involvement and grade. Screening participation was reported nationally for many factors important for risk-based screening; other reporting was ad hoc or unavailable.

Conclusions: There is potential to build on BreastScreen's existing high-quality national data collection and reporting systems to inform and support risk-based breast screening.

Implications for public health: Enhanced BreastScreen data collection and reporting would improve the evidence base and support evaluation of risk-based screening and improve the detail available for benchmarking any future changes to the program.

Key words: BreastScreen, screening outcomes, risk-based screening, breast cancer

of breast cancer three times above the population average,[11] while the Australian Government eviQ guidelines recommend annual MRI and mammography (digital or tomosynthesis) until age 50 for women with >30% lifetime risk of breast cancer,[12] or yearly mammography for women aged 40-49 years with a moderately increased risk (17-30% lifetime risk).[12] The Medicare Schedule also guides the provision of services with Medicare rebated breast imaging available by general practitioner or specialist referral, such as mammography, tomosynthesis and MRI for

asymptomatic women with a strong family history, and unilateral and bilateral ultrasound able to be requested for any woman.[13]

There is growing interest in more risk-based approaches to population breast cancer screening driven by advances in imaging technologies, community interest in personalised medicine, and the availability of well-validated tools for population-level risk assessment.[14] Key approaches being trialled internationally involve risk-targeted screening intervals and/or targeted supplemental or alternative imaging modalities, most often

incorporating information on mammographic breast density and with a focus on reducing later-stage breast cancers and interval cancers.[15-19]

In this context, Nickson and colleagues[14] proposed an evidence-based, consensus-guided framework for the review of the BreastScreen Australia program in terms of options for more risk-based screening, with consideration of risk-based surveillance services outside BreastScreen. This framework forms the basis of the Commonwealth-funded Roadmap to Optimising Screening in Australia (ROSA) project.[20] One component of the project is assessing the availability and key findings of national-level BreastScreen outcomes according to various factors of interest for risk-based screening under the current screening program. Routine reporting of such information would enhance evaluations of the existing program, help to identify priority populations likely to benefit most from risk-based screening protocols, and provide an essential benchmark against which future changes to the program could be evaluated. Factors of interest include well established breast cancer risk factors, such as hormone therapy (HRT) use or breast density, and factors important for implementing, monitoring or evaluating risk-based screening such as indicators to help ensure equity for sub-populations with existing disparities in terms of access to services and cancer outcomes.

This review assesses current and potential routine reporting of key national-level BreastScreen outcomes according to factors of interest for risk-based screening for breast cancer, identifying strengths, gaps and opportunities for potential enhanced data collection in the future.

Methods

The review is reported according to the PRISMA-ScR (Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews) checklist.[21]

Factors of interest for risk-based screening

Factors of interest for risk-based screening were prespecified according to three criteria: i) Breast cancer risk factors included in the current BreastScreen Australia data dictionary[22] and commonly reported in the Australian Institute of Health and Welfare (AIHW) BreastScreen Australia monitoring

reports,[1] ii) other well-established breast cancer risk factors included in validated breast cancer risk assessment tools,[23,24] and therefore potentially of value for implementing more risk-based screening protocols and iii) sociodemographic factors that would help establish baseline information and support monitoring of risk-based screening, such as information on sub-populations with known existing disparities in BreastScreen participation and cancer outcomes.

The resulting factors of interest are: age, Aboriginal or Torres Strait Islander status (hereafter respectfully described as Indigenous status), socioeconomic status (SES), remoteness (determined by residential postcode), location and coverage of BreastScreen service (e.g. metro, non-metro or state-wide Screening and Assessment Service locations), information reflecting client cultural and linguistical diversity (CALD) (e.g. language spoken at home, country of birth), personal history of breast cancer or ductal carcinoma in situ (DCIS), personal history of benign breast disease, family history of breast cancer or DCIS, breast density, genetic markers (e.g. BRCA1/2 mutation), reproductive risk factors, HRT use, and risk estimated by a validated breast cancer risk assessment tool. These factors were then classified according to whether they can be reported using data routinely collected by BreastScreen Australia, as specified in their data dictionary[22] or collected for other monitoring purposes.

Outcomes

Outcomes of interest were prespecified as BreastScreen Performance Indicators routinely included in AIHW BreastScreen Australia monitoring reports (participation, rescreening, recall to assessment, invasive breast cancer detection, DCIS detection, interval cancers and program sensitivity)[1] and tumour features (histology, stage, nodal status, size and hormone receptor status). BreastScreen Performance Indicators are defined in Supplementary file 1.

We also assessed whether outcomes were reported according to screening interval (annual or biennial).

Data sources and search terms

To identify routinely reported national outcome data stratified according to the factors of interest, we examined governmental BreastScreen Australia reports

obtained from the Australian Government Department of Health cancer screening website[25] and the AIHW website,[26] published from 1 January 2008 to 8 October 2020. We included publications from 2008 to target studies reporting outcomes since BreastScreen's transition from film to digital mammographic screening.

To identify additional risk-stratified outcome data that could potentially be routinely reported, we searched for relevant peer-reviewed journal articles in Medline and Embase databases for the same period. Search terms were combined for breast, DCIS, screening, mammography, and Australia and states/territories (search methods are detailed in Supplementary file 2). The AIHW BreastScreen Reference Database[27] (latest version dated 30 September 2020) was used as a secondary data source for peer-reviewed publications.

Publication selection and data extraction

Publications were selected systematically. They were included if they reported a relevant outcome stratified by a factor of interest for populations of women aged 40 years and above participating in the BreastScreen Australia program.

Eligible peer-reviewed publications included randomised controlled trials, cohort studies, case-control studies, or systematic reviews thereof. Publications reporting duplicate data, or analyses restricted to a highly selected sub-population not representative of the broader screening population (e.g. restricted to women with a rare tumour subtype) were excluded. If data were superseded in the same or another publication, only the most recent data were included. Title and abstract screening was performed by a single reviewer (CC) and the full text of relevant publications was collected for eligibility assessment. Prespecified study details and data of publications meeting selection criteria were extracted by a primary reviewer (CC) and checked by a second reviewer (LSV).

Data synthesis

Included studies and reports were summarised providing a description of the publication details (including release frequency), and data sources and linkage. Data availability was tabulated for outcomes by factor and year(s) of data collection.

Results

Literature search

Figure 1 shows the publication selection process. Of 69 reports identified on government websites, four AIHW reports met all selection criteria for inclusion; the most recent annual BreastScreen Australia monitoring report available at the time of search (2020),[1] the 2005-06 BreastScreen Australia monitoring report (published 2009) because it included more detail than subsequent reports[28] and two unique releases.[10,29] Searches of peer-reviewed literature retrieved 1,271 unique records. Of these, 1,140 references were excluded based on the title, abstract or publication type. The full texts of 131 potentially relevant references were assessed for eligibility. There were 129 articles excluded, most commonly due to not reporting an outcome or population of interest; only two relevant retrospective cohort studies[30,31] were included. No additional eligible articles were identified in the BreastScreen Reference Database. Details of the six included reports and publications are described in Table 1.

Data availability

Data availability of each outcome by factor of interest is summarised in Table 2, with information on data reporting periods.

Recent data (2013-2018) for all BreastScreen Performance Indicators considered (participation, rescreening, recall to assessment, invasive breast cancer detection, DCIS detection, and interval cancer detection rates, and program sensitivity) were reported by age [either five-yearly, 10-yearly, or for age groups according to the target age range (e.g. younger, within or older than the target age range)]. Additional BreastScreen participation data were available by age group according to Indigenous status, SES, remoteness, and language spoken at home.[1,32] Rescreening and recall to assessment rates were also reported by Indigenous status (1996-2005).[30]

Screen-detected invasive breast cancer rates were available for women with a personal or family history of breast cancer (2001-2012).[29] Invasive cancer and DCIS detection rates were reported by Indigenous status, remoteness and CALD information (most recently for 2001-2005).[10] Invasive interval cancer rates were reported by BreastScreen service location (2002-2010).[31]

Tumour size of screen-detected invasive breast cancers was available by age group (up to 2018),[1] as was tumour histology (2002-2012).[29] Tumour size, histology and nodal involvement were reported according to Indigenous status for 1991-2006.[30] We found no national-level risk-stratified data on

tumour hormone receptor status and grade for BreastScreen screen-detected cancers, nor on interval cancers.

No outcomes were available by screening interval (annual versus biennial).

Discussion

Strengths

The completeness of national BreastScreen data is remarkable considering the scale of the program (over 2.1 million women screened per year)[33] and that services are delivered by eight state and territory programs across metropolitan, regional and remote settings using a combination of fixed and mobile screening units. Additionally, each program manages its own client registry, screening and clinical data records, and links to jurisdictional cancer registries to identify interval cancers. The data collected primarily supports internal BreastScreen operational and accreditation processes, however, they are also publicly reported at a national level in a standardised and comparable format through annual AIHW monitoring reports.

Gaps

As recommended by the 2009 *BreastScreen Australia Evaluation*,[10] the quality, accessibility, consistency and timeliness of reporting

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Figure 1: Flow diagram summarising the selection process of publications included in the review.
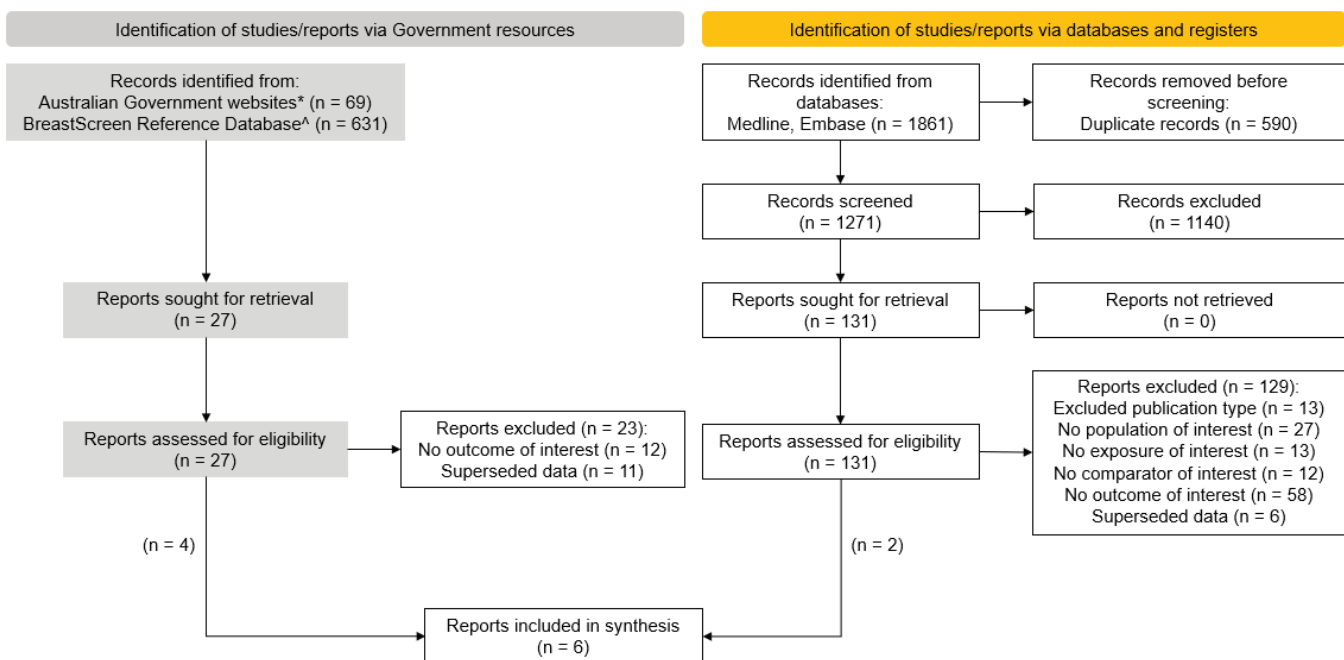
Notes:

* Department of Health cancer screening website[25] and the AIHW website[26];

^AIHW BreastScreen Reference Database (latest version dated 30 September 2020)[27]

nationally agreed standard BreastScreen data could be improved, and the data could be better used to inform policy development, enhance learning opportunities and enable strategic research. Our review indicates great potential to enhance data reporting to inform considerations of more risk-based approaches to breast screening.

Annual screening is currently the primary risk-based screening protocol used by BreastScreen, provided to around 10% of clients largely due to family history of breast cancer.[10] Unlike the Canadian program, which reports annual screening rates,[34] we did not find any data on BreastScreen Australia outcomes reported separately for annually screened women (or women offered annual screening); this limits options for evaluating the effectiveness of annual screening.[35] While national-level reporting of annual screening is likely complicated by slightly different screening policies across and within jurisdictions, and the need to distinguish between invitation to and uptake of annual screening protocols, this should be a priority for enhanced data reporting to enable evaluation of current risk-based screening protocols.

Opportunities

For the *a priori* factors of interest understood to be collected by at least some BreastScreen services, we found examples of nationally reported outcomes according to age, sociodemographic factors, and personal or family history of breast cancer or DCIS. Some BreastScreen services or research studies have collected additional data of value to considerations of risk-based screening, indicating the potential for enhanced data collection in the future. For example, HRT use is assessed at each screening episode for BreastScreen participants in South Australia,[36] Western Australia[37] and Victoria[38] (and may be collected by other jurisdictions). Several services appear to have collected information on high-risk genetic mutations,[10,39] although it is not clear if this was done systematically or on an ad hoc basis. While these data may not be able to be reported for all jurisdictions, it would be useful to assemble and report the available information.

Consideration of breast density in the context of risk-based screening is compelling due to its graded association with breast cancer risk and with risk of interval cancers and false positive recalls to assessment through its masking effect in mammography.[40-42] Breast density information is not yet collected (or assessed) nationally, following the current position by BreastScreen Australia[43] that this would require more evidence on how breast density is best assessed and managed, including evidence to support clinical pathways. BreastScreen Western Australia routinely collects and reports visually estimated breast density,[44] and a recent publication of screen-detected and interval cancers in that jurisdiction according to a range of risk factors including breast density and HRT use[37] showed associations consistent with well-established evidence in Australian and international literature.[45,46] While their method of visual assessment of breast density is not yet considered scalable to the national program, and is limited by inter- and intra-reader variability,[47] routinely reported outcomes by breast density – ideally from an automated assessment method – would aid evaluation of the current program and generate important baseline information for any risk-based screening protocols incorporating breast density. In particular, rates and characteristics of screen-detected and interval cancers according to breast density (by age group) would help evaluate the degree to which breast density reduces the sensitivity and specificity of mammographic screening and establish a baseline from which to improve outcomes for women with very dense breasts through, for example, additional or supplemental imaging.

We found that all BreastScreen Performance Indicators considered were reported recently by age. Screening participation was recently reported for many other factors of interest, however, all other outcomes were available only by age group and otherwise unavailable or not up to date. These reports indicate that more combinations of outcomes by factors of interest could be reported through additional analysis of existing data, and this seemed to be confirmed by examples of data reported in the 2009 BreastScreen Evaluation[10] and from two peer-reviewed publications. For instance, invasive breast cancer and DCIS detection have been reported by Indigenous status, remoteness and language spoken at home (CALD information),[10] while recall to assessment and rescreening rates have been reported by Indigenous status.[30]

Table 1: Publications included in the review.

Publication	Publication details	Data source (data custodian) and linkage for outcomes of interest
AIHW 2020, BreastScreen Australia monitoring report 2020[1]	Published annually to provide regular monitoring of BreastScreen Australia	State and territory BreastScreen registries Australian Bureau of Statistics population data
AIHW 2018, Analysis of breast cancer outcomes and screening behaviour for BreastScreen Australia[29]	Unique release. This report combines data from BreastScreen Australia, the Australian Cancer Database and the National Death Index.	BreastScreen registry data: NSW (Cancer Institute NSW), Victoria (BreastScreen Victoria), QLD (Queensland Health), WA (WA Department of Health), SA (SA Department of Health and Ageing), Tasmania (Department of Health Tasmania) ACT (ACT Health), NT (NT Department of Health) Probabilistic linkage to Australian Cancer Database (AIHW)
Department of Health and Ageing 2009, Evaluation of the BreastScreen Australia program – Evaluation final report[10]	Unique release. This is the final report by the BreastScreen Australia Evaluation Advisory Committee to the Australian Health Ministers' Advisory Council on the Evaluation of the BreastScreen Australia Program	AIHW BreastScreen Australia state and territory Program and data managers State and territory cancer registries
Roder et al. 2014[31]	Reports screening performance by characteristics of individual screening and assessment services (SAS) using BreastScreen Australia accreditation standards and Performance Indicators	BreastScreen Australia SAS annual data reports
Roder et al. 2012[30]	Reports data from the unique 2012 Cancer Australia report: Study of breast cancer screening characteristics and breast cancer survival in Aboriginal and Torres Strait Islander women of Australia.[51] This study provides a national overview of breast cancer screening and survival in Aboriginal and Torres Strait Islander women of Australia	AIHW (nationally aggregated data) BreastScreen Australia state and territory register data (excluding ACT) Probabilistic linkage to Australian Cancer Registries by AIHW
AIHW 2009, BreastScreen Australia monitoring report 2005-06[28]	Published annually to provide regular monitoring of BreastScreen Australia	State and territory BreastScreen registries Australian Bureau of Statistics population data

Table 2: National-level BreastScreen data reported by factors of interest for risk-based screening, and year(s) of most recent data reporting.

BreastScreen data (national level)	Factors collected by BreastScreen Australia*									Other Factors†				
	Age	Indigenous status	Socioeconomic status	Remoteness	BreastScreen service location	Information reflecting client cultural and linguistic diversity (CALD)	Personal history of breast cancer or DCIS	Personal history of benign breast disease	Family history of breast cancer or DCIS	Breast density	Genetic factors e.g. BRCA 1/2 status	Reproductive risk factors	Hormone replacement therapy use	Risk estimated by an assessment tool
BreastScreen Performance Indicators														
Participation (rates)	2017–18a / 2005–06b	2017–18 / 2005–06b	2017–18a / 2005–06b	2017–18a / 2005–06b		2017–18a / 2005–06b								
Rescreening (rates)	2016a	1996–2005f												
Recall to assessment (rates)	2018a	1996–2005f												
Program sensitivity	2013–15a													
Invasive breast cancer detection^ (rates)	2018a	2001–05d		2001–05d	2002–10e	2001–05d	2002–12c		2002–12c					
Invasive, small (≤15mm) breast cancer detection^ (rates)	2018a	2001–05d		2001–05d	2002–10e	2001–05d								
DCIS detection^ (rates)	2018a	2001–05d		2001–05d	2002–10e	2001–05d								
Interval (invasive) breast cancer detection (rates)	2013–15a				2002–10e									
Tumour features (as % of detected cancers)														
Tumour histology	2002–12c	1991–2006f												
Tumour grade														
Tumour nodal involvement		1991–2006f												
Tumour size	2018a	1991–2006f												
Tumour hormone receptor status														

Dark shading indicates data updated annually in the BreastScreen Australia monitoring report.

* *Factors routinely collected by BreastScreen Australia as or derived from items defined in the data dictionary[22] or collected for other monitoring purposes. Remoteness determined by Australian Statistical Geographical Standard residential postcode, and self-reported Indigenous status, CALD information (language spoken at home), and personal or family cancer history information is collected. Socioeconomic status is determined by Socio-Economic Indexes for Areas (SEIFA). BreastScreen service location refers to location and coverage of BreastScreen Screening and Assessment Service (SAS) e.g. metro, non-metro or state-wide.*

† *Other factors may be collected by some jurisdiction-level BreastScreen services., e.g. breast density in Western Australia.[44] Factors such as HRT use are self-reported and may be collected differently among jurisdictions.*

^ *Screen-detected*

a: AIHW 2020, BreastScreen Australia monitoring report 2020. Age-stratified data are five-yearly, 10-yearly, or for target age. Additional age-stratified participation data by five-yearly, 10-yearly, or target age are available by Indigenous status by remoteness.[1]
b: AIHW 2009, BreastScreen Australia monitoring report 2005–06. Additional age-stratified participation data by five-yearly age are available by Indigenous status, SES, remoteness, and language spoken at home.[26]
c: AIHW 2018, Analysis of breast cancer outcomes and screening behaviour for BreastScreen Australia.[29]
d: Department of Health and Ageing 2009, Evaluation of the BreastScreen Australia program – Evaluation final report.[10]
e: Roder et al., 2014.[31]
f: Roder et al., 2012.[30]

Systems to support enhanced data collection and reporting

In Australia, BreastScreen services could potentially collect more primary data, with appropriate guidelines and resourcing, noting that the BreastScreen Australia data dictionary (last updated 2019)[22] sets out minimum data reporting requirements for each state and territory service and that AIHW BreastScreen Australia monitoring reports are an ideal channel for enhanced data reporting. Internationally, there is some evidence of enhanced data collection and reporting of outcomes for breast cancer risk factors within population screening programs. For example, some Canadian screening services routinely measure and record breast density (through visual assessment), offering routine annual mammography for women with dense breasts.[48] The UK breast screening program (UKBSP) has also reported national information on genetic or familial factors (including BRCA1/2) for high-risk women undergoing alternative or supplemental MRI screening as part of its surveillance program for high-risk women.[49] These programs may offer insights about how to best establish similar reporting in Australia.

There also seems to be an opportunity for BreastScreen to report additional secondary data from cancer registries. Tumour characteristics of screen-detected and interval cancers are collected by BreastScreen services through linkage to cancer registries, which routinely collect information on tumour size, grade, nodal involvement and hormone receptor status. These tumour characteristics are all important indicators of prognosis and treatment intensity (important for any evaluation of risk-based screening), but tumour grade and hormone receptor status are not currently reported by BreastScreen at a national level, and other tumour characteristics are reported only by age or Indigenous status. The potential impost on BreastScreen services would need to be considered and suitably resourced, however work by Roder and colleagues[30] included in this review demonstrated that this type of analysis is possible. Furthermore, data linkage has been shown to improve identification of key population groups within cancer screening datasets.[50] This is particularly important for women identifying as Indigenous or from a diverse cultural or linguistic background as the BreastScreen program currently relies on self-reported information.

Limitations

This review used systematic search methods and prespecified selection criteria to identify relevant publications from nearly 2000 records. It focuses on data availability and completeness and does not assess availability of factors for incidence and mortality Performance Indicators. The scope of this review is purposefully narrow to demonstrate what is reported publicly at a national level for BreastScreen participants, and to identify opportunities for enhanced data collection and reporting. Additional data may be available at the jurisdiction level and in internal BreastScreen reports, and this may help inform priorities and processes for enhanced data collection and reporting. This information is being collected through a ROSA project activity in collaboration with the AIHW that aims to help develop protocols for enhanced BreastScreen data collection and reporting.[20]

Conclusions and implications for public health

This review highlights significant opportunities to build on high-quality BreastScreen data collection and reporting systems to enhance information available on key factors of interest for risk-based screening. Significant progress could be made through additional reporting of existing nationally assembled data, and further enhanced through national-level collection and synthesis of data routinely collected by state and territory services and cancer registries. Some important factors of interest such as breast density and HRT use are collected by only some state and territory services, but could potentially be collected nationally with appropriate guidelines and resourcing. These efforts would support evaluation of the existing program and provide a benchmark against which to assess any future changes in screening protocols, including trialling and implementing risk-based screening protocols to optimise the early detection of breast cancer in Australia.

Acknowledgement

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Supporting Information

Additional supporting information may be found in the online version of this article:

Supplementary File 1: List of definitions of BreastScreen Performance Indicators.

Supplementary File 2: Peer-reviewed literature database search strategy.