Time to Count People with Metastatic Breast Cancer

A Way Forward

Breast Cancer Network Australia

About BCNA

Breast Cancer Network Australia (BCNA) is Australia's leading breast cancer consumer organisation. We work tirelessly to ensure that all Australians who are affected by breast cancer receive the very best care, treatment and support.

About this report

This report is designed to give the sector insight into the challenges, enablers and a path forward to routine collection of stage and recurrence Australian breast cancer data. Findings are drawn from a national roundtable attended by key cancer sector stakeholders, population-based cancer registry representatives, clinical professional bodies and policymakers in August 2023. All quotes contained in this report are attributed to attendees of the roundtable.

This report was developed by Lisa Morstyn, Sam Mills and Vicki Durston from BCNA.

BCNA would like to acknowledge Professor Sanchia Aranda, Dr Jodi Steel, Dr Andrea Smith, Jodie Lydeker, Louise Sinclair, Lisa Tobin, BCNA's Metastatic Breast Cancer Lived Experience Reference Group and all attendees of the national roundtable.

Breast Cancer Network Australia acknowledges Aboriginal and Torres Strait Islander people as the traditional owners and custodians of the land, sea and nations and pay our respect to elders, past and present.

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Abbreviations used in this report.

Abbreviation	Definition
AACR	Australasian Association of Cancer Registries
AIHW	Australian Institute of Health and Welfare
BCNA	Breast Cancer Network Australia
PBCR	Population-Based Cancer Registry

Foreword from Professor Sanchia Aranda AM

Australia has rich health data collections but falls behind, like many countries do, in mobilising data to improve the health of the population. Our approach has traditionally seen data as a risk to be managed rather than an asset to be leveraged.

Data linkages that collate health data with other important information such as social determinants of health are costly to create, are subject to long delays and are established predominantly to support an individual project.

Mature data environments create perpetual data linkage assets that are updated regularly and accessible for a wide range of purposes from system performance reporting to research. Such data assets allow us to examine unwarranted variations in diagnosis, treatment and care and to monitor the impact of system improvements that seek to address disparities in cancer outcomes.

The BCNA roundtable on the collection of stage and recurrence data forms part of a new and important conversation about the need for change in how we collect, collate and manage data in Australia. Let us hope the momentum generated through this conversation will be a catalyst for lasting change.

Foreword from Vicki Durston, Director Policy, Advocacy & Support Services, BCNA

Advocacy is central to Breast Cancer Network Australia's purpose. We have known for some time that those living with metastatic breast cancer do not feel they belong amongst the 'sea of pink' and often feel invisible in the wider breast cancer sector.

Despite being raised as an issue throughout BCNA's 25-year history, we remain in 2023 with no national picture of metastatic breast cancer.

In bringing the sector together, we now have a resounding commitment to establish a roadmap and way forward together. Now is the time for change, and I am excited by what could be achieved for consumers across all cancers if we get this right for those living with metastatic breast cancer.

Executive summary

On 2 August 2023, Breast Cancer Network Australia (BCNA) convened a national roundtable in Canberra to build consensus among government and cancer sector stakeholders regarding what is needed to progress the routine capture and reporting of breast cancer stage and recurrence data across all states and territories.

There is widespread agreement about the significant challenges the lack of national breast cancer stage at diagnosis and recurrence data presents in meeting the needs of Australians affected by breast cancer. Despite this, the gap in cancer data has remained. This impedes Australia's ability to improve the outcomes of people affected by breast cancer.[1] Without national breast cancer stage and recurrence data, it is not possible to know how many people in Australia are living with metastatic breast cancer, where they live, how long before their cancer progressed and other demographic and clinical characteristics. The lack of these data hampers Australia's ability to identify national-level patterns in delayed diagnosis, cancer recurrence and survival, and to evaluate screening programs and assess new breast cancer treatments that might benefit Australians affected by breast cancer. Additionally, the lack of population-level breast cancer stage and recurrence data exacerbates feelings of 'invisibility' that many people living with metastatic disease report experiencing.[2]

About the roundtable

The roundtable was facilitated by Professor Sanchia Aranda AM, alongside BCNA CEO Kirsten Pilatti and Director Policy Advocacy & Support Services Vicki Durston, with support from key policy and advocacy staff, Sam Mills, and Lisa Morstyn. The agenda was co-designed with the project's steering committee, which included people affected by breast cancer. In total, 41 representatives attended, including representatives from the Australian Government, state and territory governments, Cancer Australia, the Australasian Association of Cancer Registries (AACR), the state and territory population-based cancer registries, professional associations and colleges, non-profits, researchers and breast cancer consumers.

The roundtable aimed to build consensus among attendees about what short-, medium- and longer-term actions would enable the routine collection, collation, reporting and use of national breast cancer stage and recurrence data. The roundtable also aimed to develop a call to action to inform future national, state and territory government policy and funding priorities, and to identify areas for further research and advocacy.

> " I think hidden in plain sight is perfectly stated that people with metastatic breast cancer are out in the community, and they're often unsupported. And I think that, by counting people, we'll begin to support them...There's very, very good services for early breast cancer, but just from my own experience [of metastatic breast cancer], you do feel like you've kind of dropped off a cliff, and a lot of people feel like that. "

A roadmap to national breast cancer stage and recurrence data: a way forward

When considering what is needed to achieve national breast cancer stage and recurrence data, attendees prioritised a number of key actions and initiatives across the short, medium and long term. These included:

1. **The prioritisation and funding of new and enduring health data linkages** – There was significant consensus among attendees that health data linkages are critical if Australia is to achieve national breast cancer stage and recurrence data, and to harness collected health data to improve the outcomes of people affected by breast cancer. The need for all state and territory cancer registries to be provided with immediate access to admitted patient care data, MBS and PBS data, and any information from oncology information systems and multidisciplinary team meeting software was also stressed to enable the trialling of new approaches to identify cancer recurrence.

2. **The need for simplified, streamlined processes governing health data access: Cancer data as an asset to leverage** – Attendees highlighted the significant time and resources currently required for researchers and other stakeholders to access health data, noting that current processes impede the ability for researchers, clinicians, non-profits and other stakeholders to harness the data.

3. **The inclusion of breast cancer stage and recurrence data in minimum cancer data sets, with cancer registries resourced to achieve the minimum standards** – Attendees stressed the need for national minimum data standards to be established, with breast cancer stage and recurrence included as core data items. Cancer Australia and the AACR were regarded as vital in building consensus about how cancer data items should be defined, methods for data capture and analysis, and data harmonisation. The variation in resourcing across the state and territory cancer registries was noted, with attendees emphasising the need for dedicated, sustained funding for breast cancer stage collection, collation and reporting.

4. **Establishment of a national cancer data strategy and framework, leveraging strengthened mechanisms for national collaboration and coordination** – Attendees highlighted the need for a national strategy to guide Australia's approach to cancer data collection, collation, reporting and use, with the inaugural Australian Cancer Plan discussed as a key mechanism for this work. Strengthened mechanisms for intergovernmental coordination and collaboration are needed, as well as greater collaboration between governments, Cancer Australia, the Australian Institute of Health and Welfare (AIHW), the AACR, state and territory cancer registries, the colleges and professional associations, non-profits and cancer consumers. Cancer Council of Australia's new Data Maturity Model was regarded as an important initiative that needs to inform the national strategy.

5. **Breast cancer as a pilot for national stage and recurrence data capture** – While national-level stage and recurrence data for all cancer types is needed, attendees discussed the value of breast cancer serving as a pilot opportunity, enabling the trialling of new approaches that could be applied to other cancer types.

> " ...[S]tarting with breast cancer is important because we can leverage what we learn from that for other cancers, so overall, we will be a more efficient registry and we can give that data on everything, but we need to start with breast cancer. "

6. **Incentivising or mandating cancer recurrence collection** – Further consideration is required regarding whether state and territory governments should mandate cancer recurrence collection via legislation, as is the approach in Victoria. While some attendees felt legislation was important, others favoured an approach focused on more strongly incentivising the collection of cancer recurrence data as well as providing education for healthcare staff regarding the importance of the cancer notification processes and the benefit of cancer data capture for people affected by cancer.

Key recommendations

Priority

1. **Fund an Australian Cancer Data Alliance** - That the Australian Government formalise and fund the Australian Cancer Data Alliance to implement the program of work related to establishing and implementing national minimum standards of cancer data collection, including national cancer stage and recurrence data. Approaches should be trialled in relation to breast cancer in the first instance, with insights applied to national stage and recurrence data capture of other cancer types. Breast cancer has a long history of leading the way, with considerable interest and momentum for this change. Several breast cancer stage and recurrence data specific pilots are also currently underway, which can inform change.

   Representation should include the Australian Government, the state and territory governments, Cancer Australia, AIHW, the AACR and representatives from the state and territory cancer registries, Cancer Council of Australia, the clinical colleges such as the Royal College of Pathologists Australasia and professional associations, health services, relevant data custodians, cancer consumer organisations including BCNA, researchers and cancer consumers.

Short-term recommendations

2. **Increase investment in state and territory cancer registries** - That state and territory governments increase investment of funding to their respective cancer registries, as required, to ensure all state and territory cancer registries have the resources to enable the routine collection, collation and reporting of breast cancer stage and recurrence data.

3. **Australasian Association of Cancer Registries** - That the AACR undertake an assessment of the state and territory cancer registries' ability to collect and/or identify breast cancer recurrence from routinely collected health data.

4. **Prioritise and fund new and enduring health data linkages** - That the Australian Government, in collaboration with the AIHW, Cancer Australia, the state and territory health departments and other relevant stakeholders, prioritise and fund new and enduring health data linkages.* As a matter of priority, all state and territory cancer registries should be given immediate access to admitted patient care data, PBS and MBS data, and any information from oncology information systems and multidisciplinary team meetings.

5. **Simplify and streamline access to existing health data** - That the Australian Government lead a project to simplify and streamline safe access to Australia's health data sets for researchers and other relevant stakeholders, so that existing health data may be more effectively utilised in research projects to improve the health outcomes of Australians.

6. **Trial new approaches to understand metastatic breast cancer prevalence** - That Cancer Australia fund the trialling of new approaches to understand the number of people diagnosed with metastatic breast cancer across the country. This could include federated learning systems and other innovative confidential data-sharing capabilities to draw analyses.†

Medium to longer term recommendations

7. **Establish dedicated funding for routine breast cancer stage and recurrence capture** – That all state and territory governments are committed to provide dedicated and enduring funding to population-based cancer registries to enable the routine collection, collation and reporting of breast cancer stage and recurrence data to form part of core business activities. Cost-effective, automated systems should also be funded for data retrieval and structured input into medical systems.

8. **Establish a national cancer data framework** – That the Australian Government, in collaboration with state and territory governments, the AIHW, Cancer Australia, the AACR, professional associations, cancer consumer organisations and other relevant cancer sector stakeholders, establish a national cancer data framework centralising leadership, accountability and minimum cancer data standards. Consideration may be given to commence this framework, as part of the Australian Cancer Plan, for breast cancer streams in the first instance.

9. **Invest in and support electronic structured reporting** – That the Australian Government and state and territory governments invest in electronic structured reporting for pathology data and imaging data, as well infrastructure to support the increased automation of cancer notification processes.

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* Data linkages bring together information from different sources to create a new, richer dataset. Data linkages enable large-scale analysis of whole populations across the healthcare system.

† Federated learning is a machine learning method that trains an algorithm via multiple independent sessions, each using its own dataset. Fundamentally, it does not require an exchange of data to centralised servers.

Introduction

1. About this report

On 2 August 2023, Breast Cancer Network Australia (BCNA) convened a national roundtable in Canberra to progress the longstanding recommendation that breast cancer stage and recurrence data be routinely collected and reported across all states and territories to enable national level breast cancer stage and recurrence data.

Facilitated by Professor Sanchia Aranda AM, alongside BCNA CEO Kirsten Pilatti and Director Policy Advocacy & Support Services Vicki Durston, with support from key policy and advocacy staff, Sam Mills and Lisa Morstyn. The roundtable brought together 41 representatives from the federal and state and territory governments, Australia's population-based cancer registries, Cancer Australia, the Australian Institute of Health and Welfare, representatives from professional associations and Colleges, non-profits, researchers, health professionals, breast cancer consumers and other relevant stakeholders.

The roundtable aimed to build consensus among attendees about short-, medium- and longer-term actions which would enable routine collection, collation reporting and use of cancer stage and recurrence data across Australia. The roundtable also aimed to develop a call to action to inform future federal, state and territory government policy and funding priorities regarding the collection, collation, linkage and use of cancer data, as well as identify areas where further research and/or advocacy is needed.

This report summarises the discussions from the roundtable and key actions identified by attendees as needed to progress national breast cancer stage and recurrence data capture and reporting. It also details key findings from a pre-roundtable survey BCNA conducted with attendees to explore key barriers, enablers, opportunities and potential solutions in the lead up to the roundtable to ensure the event was action-oriented and solutions-focused.

2. Why now? Harnessing cancer stage and recurrence data for improved breast cancer outcomes

It has been widely recognised that Australia's lack of routine national breast cancer stage and recurrence data hampers the efforts of Australian governments and health services to plan for, and meet the complex physical, psychosocial and supportive care needs of people living with metastatic breast cancer resulting in poorer outcomes. These data would also allow analysis of the quality of care and assessment of factors to determine variations in cancer outcomes. This has long been a priority for BCNA's members, who also report this lack of data contributes to feelings of 'invisibility' among individuals diagnosed.[3] While all Australian states and territories have a population-based cancer registry (PBCR), the registries' primary role when established was to collect data about cancer incidence and mortality. As a consequence, Australia's PBCRs do not routinely capture cancer stage and recurrence data.[4] This issue is further explored by BCNA in its 2022 'issues paper,' Making Metastatic Breast Cancer Count.

Without population-level breast cancer stage and recurrence data, it is not possible to know how many people are living with metastatic breast cancer across Australia, nor where they live, their age and other demographic and clinical factors that may impact their diagnosis and outcomes. It is not possible to identify, analyse or track population-level trends in late breast cancer diagnosis, to understand the impact at a population level of improved diagnostics and treatment on recurrence and post-metastatic survival, or to understand who across the country may not be receiving optimal care.

While modelling can provide estimates of metastatic breast cancer prevalence, such estimates are unlikely to represent the true number of people affected by metastatic disease. This is because development in genomic testing, new drugs and directed therapies, mean people with metastatic breast cancer are living longer than in past decades, which is not reflected or updated in pre-existing models.[5] Cancer Australia's 2008 National Cancer Data Strategy for Australia also cautioned that the use of modelling must not 'impede the collection of metastatic breast cancer data' as such data is vital for 'outcome monitoring' and research.[6]

In recent years, the need for enhanced national cancer data to inform policy, service design, health workforce planning and budget allocation has become particularly pressing. The COVID-19 pandemic caused significant disruptions to cancer screening, diagnosis, treatment and supportive care services and raised concerns about the impact of delayed and late-stage cancer diagnoses on the health outcomes of Australians diagnosed with cancer.[7] The ongoing impacts of the COVID-19 pandemic, such as reduced screening, will continue to increase later-stage cancer diagnoses and place further pressure on health services across the country.[8] Population-level breast cancer stage and recurrence data would also enable evaluation of screening and early detection initiatives as well as the faster assessment of new tests and treatments that may benefit Australians affected by breast cancer. Ultimately, the smarter, more effective use of cancer data, including population-level breast cancer stage and recurrence data would enable improved clinical, psychosocial and supportive care outcomes for people affected by breast cancer across the country.

The need for reform of Australia's approach to cancer data collection, collation, reporting, use and linkage has been highlighted in the new 10-year Australian Cancer Plan. In the Plan, cancer data is identified as a key pillar underpinning the provision of optimal cancer care and an important asset that will improve the outcomes of Australians affected by cancer across the country. In 2015, Cancer Australia undertook the Stage Treatment and Recurrence (STaR) project to explore different methodologies to collect national cancer stage information, and Cancer Australia has emphasised the importance of such data to identify national variation in stage of diagnosis and patterns of cancer recurrence.[9]

Many stakeholders across the sector are also calling for reform; for instance, Cancer Council Australia has recently worked with a range of key stakeholders to develop a new cancer data maturity model, which would enable cancer data to be more effectively utilised to monitor the provision of health services and to identify and address inequities in cancer care and cancer outcomes.[10] Several pilot studies are underway to inform methods to capture metastatic breast cancer prevalence and demographics within the data available to the population-based cancer registries.

However, despite a decades-long agreement and advocacy by stakeholders about the need for population-level cancer stage and recurrence data, the gap remains, challenging the efforts of governments, clinicians, researchers, non-profits and others to leverage national cancer data to monitor the provision of optimal care and to improve the outcomes of Australians affected by cancer.

3. The Approach: co-designed with people affected by breast cancer

On Metastatic Breast Cancer Awareness Day in 2022, BCNA released its inaugural issues paper, *Making Metastatic Breast Cancer Count*, which highlighted the complex and often unmet needs of people with metastatic breast cancer, and the challenges the lack of consistent stage and recurrence data presents for cancer policy development, health system investment and planning, service delivery and research.[11] This paper also sought to utilise updated modelling to

give a conservative estimate of there being at least 10,500 Australians living with metastatic breast cancer in 2020.

Following the release of the issues paper, BCNA commenced planning for a national roundtable to be held in early August 2023 in Canberra to bring together government representatives, epidemiologists, representatives from the population-based cancer registries, professional associations, breast cancer consumers and other relevant stakeholders to discuss how best to achieve national cancer stage and recurrence data.

In the 6 months prior to the roundtable, BCNA staff conducted extensive stakeholder engagement, canvassing the sector to ensure the most appropriate sector experts were selected to lead at the roundtable. The purpose was to ensure we selected the most appropriate experts who could contribute to consensus-building and decision-making, and key sector leaders to help guide best practice models as a preparation strategy.

A National Roundtable Project Steering Committee was convened by BCNA to guide the design and implementation of the project. Membership included 2 BCNA Consumer Representatives living with metastatic breast cancer and 2 BCNA Consumer Representatives diagnosed with early breast cancer. Project direction was also informed by sector leaders including Professor Sanchia Aranda. The Steering Committee co-designed the objectives and agenda for the roundtable with BCNA's Project Team and advised on the approach to stakeholder engagement and consensus building.

A Communications Working Group comprising BCNA members living with metastatic breast cancer was convened to guide the development of external communications and messaging. The campaign message 'I Count Too' and imagery was co-designed with the Communications Working Group.

BCNA engaged with representatives from state and territory governments, Cancer Australia, the Australian Institute of Health and Welfare (AIHW), the Australasian Association of Cancer Registries (AACR) and each of the state and territory PBCRs, given their expertise and direct involvement in cancer data collection, collation, analysis and/or reporting.

BCNA also sought to involve a broad range of cancer sector organisations, professional associations, cancer clinicians and researchers who have a wealth of expertise across areas such as epidemiology and population health, multidisciplinary cancer care, health economics, law, digital technology and health data linkage.

In total, 41 representatives attended the national roundtable. To ensure that the needs, interests and experiences of people affected by breast cancer remained central to roundtable proceedings, the 4 breast cancer consumer representatives, including 2 with metastatic breast cancer, also participated.

Pre-reading information pack

Prior to the roundtable, BCNA circulated a pre-reading information pack, which provided attendees with information about the aims of the roundtable as well as the key barriers, enablers, opportunities and potential solutions shared with BCNA via the pre-roundtable stakeholder engagement. The pre-reading also acknowledged the significant work of many individuals and organisations to enhance cancer data capture, reporting and use, and provided and summarised a number of key projects related to cancer stage and recurrence data.

Prior to the roundtable, Cancer Council Australia also kindly provided roundtable attendees with an embargoed copy of the draft report, *Developing a National Strategy for Cancer* - **Developing a National Strategy for Cancer**, which details a cancer data maturity model Cancer Council Australia has developed in consultation with key stakeholders. The high-quality data to be achieved under the model would enable health system performance assessment and benchmarking, evaluation of prevention, screening and early intervention programs, analysis of patterns and trends relating to demographic and disease characteristics, cancer outcomes and health system planning. BCNA considers Cancer Council Australia's Data Maturity Model to be a key document, which

should underpin the approach to cancer data collection, collation, reporting, linkage and use developed as part of the new Australian Cancer Plan.

The full pre-reading information pack is available from BCNA upon request.
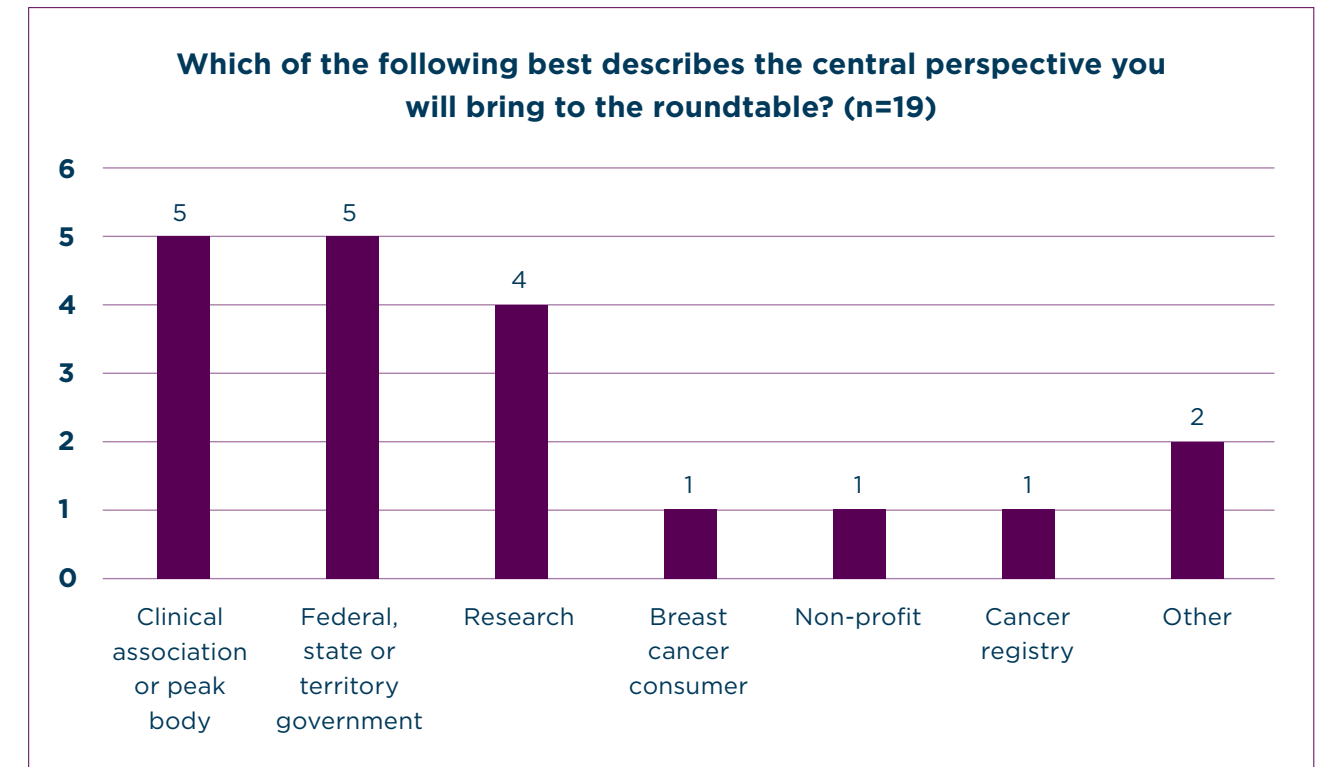
Pre-roundtable survey

BCNA conducted a pre-roundtable survey with stakeholders who would be attending the roundtable. Attendees were asked to rank the top barriers and challenges across the areas of (1) governance, policy and legislation, (2) data, processes and linkage, and (3) resources and technology. Attendees were also asked to rank the most significant enablers and opportunities. Responses were compared using a weighted average.

The survey also asked about key areas of investment that should be prioritised to progress national stage and recurrence data, with attendees asked to allocate a hypothetical $100 across a range of areas, such as existing cancer registry infrastructure, new technology and the workforce available to hospitals/health services to submit cancer notifications. The survey tool is provided in Appendix B.

In total, 19 attendees completed the survey, representing a range of perspectives. Key findings were presented at the roundtable and are discussed in this report.

Figure 1: responses to pre-roundtable survey.

Which of the following best describes the central perspective you will bring to the roundtable? (n=19)

- Clinical association or peak body: 5
- Federal, state or territory government: 5
- Research: 4
- Breast cancer consumer: 1
- Non-profit: 1
- Cancer registry: 1
- Other: 2

Roundtable format and agenda

The roundtable involved a series of plenary sessions from key experts and champions within the sector to share their insights of work to date, pre-roundtable survey results , 'quick fire' presentations and group workshops, and a prioritisation exercise that asked attendees to prioritise potential solutions developed in the workshops across the next 2, 5 and 10 years (in line with the timeframe set out in the 10-year Australian Cancer Plan). Roundtable sessions were recorded to assist with the roundtable write-up. To enable full and frank discussions, Chatham House rules applied, and roundtable attendees were assured that any material developed by BCNA regarding the roundtable would not include attribution of statements to individual attendees, unless explicit permission had been sought.

The program was co-designed with BCNA's Project Steering Committee, with input from Professor Sanchia Aranda AM, Cancer Council Australia, representatives from the PBCRs and other key stakeholders.

The agenda was structured around the 2 broad themes of 'capacity' and 'access', with 3 areas of specific focus:

1. Data and processes	Data items, definitions, data harmonisation and quality, cancer notification and reporting processes, and data linkage
2. Resources and technology	Funding, workforce, technology (e.g. artificial intelligence), systems
3. Governance and policy	Legislation, policy, regulation, privacy/access, data custodianship

Presentations covered a range of topics, including:

- the new Australian Cancer Plan

- opportunities if Australia invested more funding into its cancer data system

- innovations in technology that could be utilised

- the importance of health data linkages in identifying cancer recurrence

- international case studies that might inform Australia's approach

- findings of the pre-roundtable attendee survey.

Two workshops were run, with attendees divided into 3 groups to reflect the 3 areas of focus and asked to consider the following:

1. What are the most pressing challenges or barriers that are preventing the routine collection/collation, reporting and use of cancer stage and recurrence data?

2. What are 4 or 5 actionable recommendations that could progress the routine collection/collation, reporting and use of cancer data in the future, with consideration given to opportunities and enablers, timing and sequencing, and accountability.

After briefly acknowledging the challenges early in the roundtable, the focus was deliberately action driven, with facilitation redirecting the group towards change and next steps.

A multidisciplinary approach to the groups was taken, with attendees from various specialities allocated across the groups to ensure a variety of perspectives in each group.

A BCNA Consumer Representative, who was also part of the Project Steering Committee, was appointed to each of the 3 groups to contribute the consumer perspective. A BCNA staff member led discussion in each group, with support provided by the consumer representatives. Staff reported back to the larger group, drawing on knowledge gained from pre-roundtable stakeholder engagement, and time was provided for group discussion and deliberation.

In the final session of the day, attendees were asked to consider the solutions identified in the workshop session, and to prioritise the solutions across the coming 10 years. Each attendee was also given the opportunity to verbally share reflections on their own commitments to change.

Summary of roundtable discussions and key areas of consensus

1. National breast cancer stage and recurrence data must be regarded as 'critical data'

In the pre-roundtable survey and throughout the roundtable, attendees stressed that routine, population-level breast cancer stage and recurrence data must be viewed as 'core [cancer] data' and prioritised by governments, health services and other relevant stakeholders. Attendees highlighted a wide range of benefits to the systematic and routine collection of population-level breast cancer stage and recurrence data.

Benefits included:

- National breast cancer stage and recurrence data would illuminate trends in delayed diagnosis and the detection of recurrences, enabling the development of more targeted approaches to screening and early detection.

- The data would allow for new tests, scans and breast cancer treatments to be assessed more quickly and at the population level, leading to enhanced identification of effective tests and treatments for Australians affected by breast cancer.

- The data would allow greater understanding of demographic, geographic and clinical factors impacting breast cancer diagnosis and outcomes, including why the significant gap in cancer outcomes between Indigenous and non-Indigenous Australians remains.

> " *Without this data it is impossible to truly know...are we delivering equitable care, equitable outcomes across the regional, remote, very remote, metro populations, your Aboriginal, non-Aboriginal populations, your cultural, linguistic, diverse populations, often forgotten group people living with disabilities, are they receiving equitable care as well? It's absolutely critical for that.* "

- The data would enable efficiencies in government and health sector expenditure due to improved understanding of where investment is most likely to improve outcomes and address unmet needs of people affected by breast cancer.

> " *The benefit to [governments] is that they have a much better idea of how to control their spend, and they have a better idea of how to understand and explain to the taxpayer the benefit of that spend in early disease and metastatic across the whole cost of the care of that patient, and to target those areas that are inequitable.* "

> " *The benefit to [governments] is that they have a much better idea of how to control their spend, and they have a better idea of how to understand and explain to the taxpayer the benefit of that spend in early disease and metastatic across the whole cost of the care of that patient, and to target those areas that are inequitable.* "

- The data would provide a more comprehensive understanding of population-level patterns in diagnosis, recurrence and survival, opening up new areas of research, clinical trials and interventions to address variations and inequities in breast cancer outcomes.

2. Data as an asset: leveraging breast cancer data for improved outcomes

Many roundtable attendees discussed the need for greater recognition by governments and Australian society more broadly that health data is a key asset to leverage, rather than predominately a risk to manage. While the importance of data governance, privacy and security arrangements were noted, the group emphasised that a balance is required, whereby such arrangements do not prevent or unduly constrain cancer data access, sharing, linkage and use for purposes such as cancer research, health service performance monitoring, workforce planning, clinical trial recruitment, the evaluation of interventions and the analysis of national trends.

Australia was characterised as 'decades behind' comparable international jurisdictions in harnessing cancer data to develop and evaluate cancer policies, programs and services.

> " *[W]e have in front of us the evidence that we need to improve the health system, and that means living lives, all of us living our lives in better ways, but we don't use that data. We're decades behind.* "

The need for a cultural change, which would see greater recognition of the value of cancer data capture across hospitals and health services, was also discussed. Attendees highlighted the time and resourcing required for cancer data capture by health services, with some attendees indicating that cancer data capture should be more strongly incentivised by governments and other relevant stakeholders. Other attendees felt that if there was a greater education of healthcare workers across public and private health services about why population-level cancer data collection is important and how it can be harnessed to improve the cancer outcomes of people, this would encourage a greater prioritisation of data capture for cancer notification purposes.

3. The need for leadership, interjurisdictional collaboration and national minimum data standards, including stage and recurrence data

Roundtable attendees stressed the need for the immediate prioritisation, action and investment in Australia's cancer data system by the federal and state and territory governments, with the new 10-year Australian Cancer Plan regarded as a key opportunity to progress national breast cancer stage and recurrence data.

While the complexities of population-level breast cancer stage and recurrence data were acknowledged, attendees stressed that the challenges must not continue to act as a deterrent to action and investment, as national data are achievable if prioritised nationally and across the states and territories. International examples were cited, such as Canada where cancer stage at diagnosis data has been routinely collected by all provinces and territories except Quebec since 2010 for breast, prostate, colorectal and lung cancers,[12] and this data has been utilised by government, health services, clinicians, researchers and other key stakeholders across the country.

> [T]here are other countries who collect this information, it can be done. Australia, with all of its wealth and its desire to do certain things, and it plays as a national or a huge player in the international stage, it can be done. We really need to think through today…what those roadblocks are and just figure out how to bust through them.

There was strong consensus about the need for the establishment of minimum national cancer data standards, which include breast cancer stage and recurrence as core cancer data. While each Australian state and territory government is responsible for establishing the cancer notification requirements in its jurisdiction, attendees emphasised the need for national-level agreement that breast cancer stage and recurrence data must form part of Australia's minimum national cancer data standards if Australia is to achieve population-level stage and recurrence data.

New and strengthened mechanisms for inter-governmental coordination and collaboration were regarded as critical given the goal of national-level breast cancer stage and recurrence data; however, attendees also advised that enhanced mechanisms must be developed to facilitate improved collaboration between governments, Cancer Australia, AIHW, AACR, PBCRs, clinical groups and professional associations, researchers, non-profits and cancer consumers. Such mechanisms were regarded as vital for stakeholders to discuss and reach agreement about data-related issues, such as how cancer recurrence should be defined, and to address the fragmentation of initiatives and research projects that exists across the country. As one attendee noted:

> I hear a lot of these things and I think, 'Oh, we tried that and it didn't work,' or, 'We know how we can do that.' [T]here's no sharing, there's no ability for people to learn off each other.

Recent advances in technology relating to data capture, collation, analysis, linkage and access were also highlighted, with attendees discussing the opportunity available to Australia to harness innovation to design an integrated cancer data system that will serve Australia now, but also well into the future.

> As much as Australia may be a little bit behind, I think now is the opportunity for Australia to say, 'How do we leapfrog forward? How do we perhaps go beyond what…other jurisdictions have been doing for 20 or 30 years, and really make it cutting edge? How do we make it worthy of our implementation that's going to hold us for the next decade or so?' I think that that is an opportunity.

4. Cancer registries as a key vehicle for change

Throughout the roundtable, attendees stressed the importance of Australia's state and territory PBCRs as a key vehicle to enable national-level breast cancer stage and recurrence data. The AACR was noted as a key collective representing the registries in driving this change. Across the day, the depth of expertise and commitment of the cancer registries to cancer data collection, collation, analysis and reporting was underlined. Yet despite the vital role of cancer registries in achieving population-level cancer data, many attendees felt that the value of registries has not been sufficiently recognised by governments or the broader health sector, as evidenced by the significant resourcing constraints many of the registries operate under.

…None of us have any resources to do it and we're all pretty much cobbling together our registries on very limited resources as it is. So, whilst we are really, really keen, we really need to get some support…We fight for our funding every year. Most of us have a large temporary workforce that we also employ to just keep going.

At the roundtable, several attendees posited that progressing routine breast cancer stage and recurrence data capture by some of the more well-resourced state and territory cancer registries may be an important first step; however, the need for nationwide breast cancer stage and recurrence data collection, collation and reporting was stressed if Australia is to ensure that all people affected by cancer have access to optimal cancer treatment and care. A number of attendees noted that Australia-wide data is constrained by the cancer registries with the most limited funding and capabilities, which is therefore an issue that all states and territory governments and the broader cancer sector must together address.

5. The need for reform of Australia's existing processes governing access to health data

Throughout the roundtable, attendees stressed the need for urgent reform of Australia's existing processes around data access. Attendees pointed to the significant time and resources required by researchers and other stakeholders who apply to access existing health data sets for research and other purposes. One attendee described waiting over 3 years to access the health data sets needed for a record linkage research project, and attendees noted that this was the norm.

> **"** *Three years later, $250,000 spent on staff and time to actually do this, not including any of my time, and we're nowhere near that.* **"**

Ultimately, there was considerable consensus among attendees that, while enhanced data capture is vital, the benefits of cancer data collection cannot be translated into improved outcomes for Australians affected by breast cancer if access to the data remains so constrained.

> **"** *I think there really does need to be a wake-up call around how we access this data and how that functions in Australia, if we really want to use this data to drive the system forward.* **"**

6. The need for the prioritisation and funding of new and enduring health data linkages

There was substantial consensus among attendees that health data linkages are critically important if Australia is to achieve national breast cancer stage and recurrence data, as well as improve the outcomes of Australians affected by breast cancer. Health linkages enable data from multiple sources to be connected, enabling new insights about the impact of personal, clinical, lifestyle and other factors on health outcomes.

Attendees discussed Australia's existing national data linkage infrastructure, emphasising the need for new routine and enduring national health data linkages to be established and funded. It was recommended that each of the state and territory PBCRs be provided with immediate access to admitted patient care, MBS and PBS data to enable analyses aimed at identifying breast cancer recurrence. National linkages between CaT-Link1*, the cancer registries, MBS, PBS and admitted patient care data were also recommended.

7. Key barriers to national breast cancer stage and recurrence data

In the pre-roundtable survey and throughout the roundtable event, attendees identified a range of key barriers and challenges, which must be addressed if Australia is to achieve national-level breast cancer stage and recurrence data. Discussion of the challenges to population-level stage and recurrence data informed the development of recommendations regarding what is needed in the short, medium and longer term to progress breast cancer stage and recurrence data capture across Australia.

The key challenges and barriers identified by attendees in the pre-roundtable survey are summarised in Table 1, and a more extensive analysis is set out in Appendix C.

* CaT-Link AA Phase 1 are multi-sourced, enduring, linked data sets, including the cancer and treatment linked analysis asset (CaT-Link AA) rolled out through the AIHW. Phase 1 of the project aims to establish an enduring link between CaT-Link AA assist with cancer-related epidemiological research.

Table 1: Most significant barriers and challenges identified by attendees via the pre-roundtable survey

Governance, legislation, policy-related barriers/challenges (n = 17)
1. Insufficient prioritisation of cancer stage and recurrence data collection/collation and reporting by policymakers
2. Differing state and territory legislative arrangements regarding cancer notification requirements
3. Complexities regarding Commonwealth and state/territory health data governance and data custodianship arrangements
4. Concerns about data security and privacy

Resourcing-related barriers/challenges (n = 18)
1. Lack of dedicated funding for cancer stage and recurrence data collection/collation
2. The manual nature of many cancer notification and registration processes
3. Cancer registry workforce constraints

Technical barriers/challenges (n = 18)
1. Challenges relating to structured reporting of pathology data
2. Methodological complexity relating to cancer stage or recurrence data collection/analysis
3. The lack of an agreed national definition of cancer recurrence
4. Lack of routine and enduring health data linkages

8. Prioritisation of recommendations and timeframe for change

In the final session of the day, attendees were asked to consider the solutions identified in the workshop session and to prioritise them over the coming 10 years. Each attendee was given 15 stickers, which they could place next to the solutions to be prioritised. Attendees were also asked to consider timing, placing red stickers next to solutions that should be prioritised in the next 2 years, yellow stickers next to solutions to prioritise in the next 2 to 5 years, and green stickers next to solutions that should be prioritised over 5 to 10 years. Each attendee was given 5 stickers corresponding to each timeframe, with instructions to allocate all 15 among draft recommendations. Following voting, attendees discussed the solutions/approaches that had been prioritised most highly, considering issues of implementation, sequencing and resourcing.

The following table sets out the verbatim actions prioritised by the attendees, aligned to the timeframe set out in the 10-year Australian Cancer Plan.

These actions formed the basis of the final recommendations outlined at the start of this report. They underwent further stakeholder consultation with consideration of roundtable discussions, plenary sessions, presentations and workshops during refinement.

Table 2: Recommendations prioritised during the roundtable

Prioritised recommendations	0	1	2	3	4	5	6	7	8	9	10
							Years				
Derive metastasis data from existing and linked registry data (Definition to be guided by AACR stage at diagnosis).		▓	▓								
Resource smaller or less resourced registries to achieve minimum standards.		▓									
Link data sets nationally and fund ongoing use. Data sets to be included: cancer registry data, MBS, PBS, inpatient and Cat-Link.		▓									
Aim for 100% of breast cancer patients discussed in multidisciplinary meetings and data inputted in standardised software and available to registries/users.		▓									
For PBCR that do not have access, establish linkages between state and territory cancer registries and MBS, PBS and inpatient data sets, with resourcing provided for unique state and territory needs.		▓									
Develop a national cancer data strategy and framework.		▓	▓			▓					
Fund and mandate electronic reporting of all cancer registries, including necessary upgrades of cancer registry infrastructure.					▓	▓					
Develop and use agreed data indicators for accountability.						▓	▓	▓			
Apply minimum data sets to electronic medical record systems (structured reporting) and applied to public and private systems.						▓	▓	▓	▓		
Establish a national legislative authority with responsibility and oversight of minimum data sets.						▓	▓	▓			
Fund validity testing to provide strengthened evidence regarding health data linkages identifying cancer recurrence.						▓	▓	▓	▓		
Mandate registry minimum data sets to include cancer stage and recurrence.						▓	▓	▓			

9. Commitment to change

To close the roundtable, each attendee was also given the opportunity to verbally share reflections on the following:

1. What do you see as the main benefit of collecting cancer stage and recurrence data?

2. To help maintain momentum from the roundtable, what is one commitment you or your organisation would like to make regarding the next steps?

Some of these reflections captured during this section of the agenda are included at Appendix A. The resounding consensus from attendees was that it will take sector-wide commitment, investment, action and advocacy to fully realise the roadmap and recommendations discussed during the day. The significant value of these data, coupled with the timing and need for change, was discussed and agreed by the group, as captured by the quote from Professor Sanchia Aranda below. Attendees also expressed interest in formalising a collaborative group consisting of the roundtable attendees, and other interested stakeholders, as a forum to drive actions and maintain accountability.

> **"**
> *The critical message is that we have the capacity, the knowledge, and the tools to improve cancer outcomes today ... I think equity is probably the most important rationale for changing the data system.*
> **"**
>
> *– Professor Sanchia Aranda*

Conclusion

Roundtable attendees agreed that the time is now to improve breast cancer information in our cancer registries. There was consensus that this is vital information which could improve the care and experience of breast cancer consumers, and cancer consumers more broadly. Attendees stressed that it is vital to know how many people live with metastatic breast cancer in Australia for resource allocation, health system planning, incentivising clinical trials, medication subsidy and supportive care.

As noted by one attendee, 'Breast cancer has a long history of leading the way.' This highlights the opportunity to trial new approaches for breast cancer data collection and then apply these insights to other cancers to improve equity in care and outcomes.

There was also considerable value reported in bringing the sector together, including many stakeholders who had not previously interacted despite considerable synergies in their respective work.

Involving those affected by breast cancer not only in roundtable discussions but in the project co-design ensured that those who stand to see the most benefit from improvements to our cancer data were central to conversations. BCNA is well placed to continue consumer-led advocacy work in this space.

BCNA now calls on decision-makers to urgently consider the roadmap and recommendations contained in this report, and to work with the sector on meaningful action for a way forward to **make metastatic breast cancer count**.

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Appendix A: Reflections from roundtable attendees

Why now? The case for the urgent prioritisation of population-level breast cancer stage and recurrence data

The following section sets out key quotes from attendees regarding why national breast cancer stage and recurrence data is important and why its collection should be immediately prioritised by the federal and state and territory governments and cancer sector stakeholders.

Attendees highlighted the importance of population-level breast cancer stage and recurrence data to:

Evaluate cancer screening programs and other early detection activities

> *Routinely collected and linked national population level cancer stage data is a core data element in the cancer data ecosystem to unlock more potential from the existing cancer data for monitoring and evaluation of programs and initiatives such as screening programs. (Pre-roundtable survey respondent)*

Assess the efficacy of new tests, scans and treatments

> *…being able to see gains in post-metastatic survival and how that's distributed across the community, particularly in needy groups and remote groups and the like. And maybe getting an earlier window on whether new drugs are having an effect rather than waiting, at the population level, for death statistics to arrive.*

Understand population level changes and trends in cancer diagnosis, recurrence and survival

> *This information is essential for surveillance and epidemiological cancer research…Stage and recurrence data would allow enumeration of the metastatic/ advanced population, which would then allow for epidemiological studies that could identify and track adverse events, long-term outcomes related to metastatic/advanced cancer and its treatment. (Pre-roundtable survey respondent)*

Identify and address inequities in cancer care and outcomes

> *Without this data it is impossible to truly know…are we delivering equitable care, equitable outcomes across the regional, remote, very remote, metro populations, your Aboriginal, non-Aboriginal populations, your cultural, linguistic, diverse populations, often forgotten group people living with disabilities, are they receiving equitable care as well? It's absolutely critical for that.*
>
> *[I]t's time to make this equitable. It shouldn't matter where you're diagnosed or where you live. You should have access to the best treatment and the best care, and that includes some of this data that drives those innovations.*
>
> *[S]tage of cancer at diagnosis is the most important predictor of survival, and if you can't get that, then, you can't possibly tell the story of inequity in our health system. It's just such a critical data field to look at priority populations, to be able to see whether the cancer plan is actually working, to assess screening programmes. It just is critically important.*
>
> *I want [data captured] for everyone… from a clinical trials perspective, we can have greater equity and access to clinical trials if we know where these people are.*

Enable more efficient and targeted budget planning, allocation and investment

> *The benefit to [governments] is that they have a much better idea of how to control their spend, and they have a better idea of how to understand and explain to the taxpayer the benefit of that spend in early disease and metastatic across the whole cost of the care of that patient, and to target those areas that are inequitable.*

Harness breast cancer data for improved outcomes using data as a key asset

> " *[The] good use and smart use of data brings strength and opportunity rather than risk if it's done well.*
>
> *It's about value. Data is an asset that we have and that we want to build on and use to improve outcomes…breast cancer has a long history of leading the way for other cancers, and I think that's the opportunity here, to get it right in breast cancer, and then, to be able to think about other people with metastatic and advanced disease and how their outcomes can be improved.*
>
> *[W]e have in front of us the evidence that we need to improve the health system, and that means living lives, all of us living our lives in better ways, but we don't use that data. We're decades behind.*
>
> *As much as that Australia may be a little bit behind, I think now is the opportunity for Australia to say, 'How do we leapfrog forward? How do we perhaps go beyond what…other jurisdictions have been doing for 20 or 30 years, and really make it cutting edge? How do we make it worthy of our implementation that's going to hold us for the next decade or so?' I think that is an opportunity.* "

Move forward with population-level breast cancer stage and recurrence data because it is achievable

> " *I know it's complicated, but just hearing what's happening in [international jurisdiction] made me think, 'Oh, why have we delayed?' And I think it's really time to stop delaying.*
>
> *[T]here are other countries who collect this information, it can be done. Australia, with all of its wealth and its desire to do certain things, and it plays as a national or a huge player in the international stage, it can be done. We really need to think through today…what those roadblocks are and just figure out how to bust through them.* "

Appendix B: Pre-roundtable survey instrument

Survey Questions

Question 1:

Which of the following best describes the central perspective you will bring to the roundtable?

- Federal, state or territory government
- Population-based cancer registry representative
- Representative of a clinical association or peak body
- Non-profit
- Breast cancer consumer
- Research
- Other _____

Question 2:

At the national roundtable, one of the workshop sessions will involve a discussion of the key barriers and challenges to the routine collection/collation and reporting of breast cancer stage and recurrence data across all states and territories.

Below are some of the key barriers and challenges reported to BCNA via our pre-roundtable stakeholder engagement.

Please rank the top **5 barriers/challenges** in order of significance? (1 = the most significant barrier/challenge). The barriers/challenges below have not been listed in any particular order.

Policy, governance, and legislation

1. Insufficient prioritisation of cancer stage and recurrence data collection/collation and reporting by policymakers
2. Complexities regarding Commonwealth and state/territory health data governance and data custodianship arrangements
3. Concerns about data security and privacy
4. Differing state and territory legislative arrangements regarding cancer notification requirements

Resourcing constraints

1. Lack of dedicated funding for cancer stage and recurrence data collection/collation
2. The manual nature of many cancer notification and registration processes
3. Insufficient investment in new technologies, such as AI
4. Cancer registry workforce constraints
5. Hospital/health service workforce constraints
6. The number of different tumour types constrain registries' capacity to stage breast cancer cases
7. The time and costs for researchers applying for permission to link health data sets

Technical issues

1. The lack of an agreed national definition of cancer recurrence
2. Methodological complexity relating to cancer stage or recurrence data collection/analysis
3. Lack of routine and enduring health data linkages
4. Challenges relating to structured reporting of pathology data
5. Population based cancer registries' lack of access to imaging data
6. Different staging systems used by Australian state and territory cancer registries

Do you have any additional barriers to add? _____

Question 3:

The following enablers and opportunities for the routine collection/collation and reporting of cancer stage and recurrence data have been reported to BCNA via our pre-roundtable stakeholder engagement.

Please rank the top **5 enablers/opportunities** in order of significance? (1 = the most significant enabler/opportunity)

Enablers/opportunities

1. There is widespread agreement about the need for cancer stage and recurrence data to inform cancer policymaking and planning

2. The new 10 year Australian Cancer Plan highlights the need for a comprehensive cancer data ecosystem in Australia

3. There is increasing demand for staging data by hospitals and the clinical community to enable service planning and delivery.

4. Cancer Australia's Cancer Stage, Treatment and Recurrence (STaR) project generated significant insights into methodological approaches regarding registry derived data

5. New technology, such as artificial intelligence, has the potential to automate PBCR processes, saving time and resources.

6. A number of research projects and initiatives underway across Australia are aimed at progressing the routine collection/collation and/or reporting of cancer stage and recurrence data.

7. International initiatives provide important insights that may inform Australia's approach to national cancer stage and recurrence data collection/collation and reporting

8. The Australian Government and state and territory governments are significantly investing in digital health strategies, initiatives and programs (e.g. Australian Digital Health Agency, MADIP)

9. Changing societal attitudes regarding the use of health data to inform decision-making

10. Increasing use of digital technology within Australia's health-care system (e.g. electronic prescribing, telehealth)

Do you have any additional enablers or opportunities to add? _____

Question 4:

If you had $100 to invest in routine breast cancer stage and recurrence data collection/collation and reporting across all Australian states and territories, how would you allocate it across the following areas?

- Existing state/territory population-based cancer (PBCR) registry infrastructure (e.g., ICT systems, software, facilities) _____

- PBCR workforce (e.g., coders, staff training) _____

- Funding for artificial intelligence, automation and other new technologies into PBCRs _____

- Hospital/health services workforce involved in cancer notification processes (e.g., workforce, staff, systems) _____

- Funding to enable health data linkages _____

- Other _____

Comments: _____

Question 5:

Do you have any other comments or considerations that should be taken into account at the roundtable, including why collection/collation, reporting and use of population level cancer stage and recurrence data is important and/or how this data could be used to improve cancer outcomes? _____

Appendix C: Extended analysis: most significant barriers and challenges to population-level breast cancer stage and recurrence data

A key aim of the pre-roundtable survey and first roundtable workshop session was to identify and develop consensus regarding what the most pressing barriers are, which must be addressed for Australia to achieve routine and systematic population-based national breast cancer stage and recurrence data.

Challenges and barriers were discussed in relation to the following 3 areas of focus:

1.   Data items, processes and linkage

2.   Resourcing and technology

3.   Governance, legislation, policy and regulations

Key data, processes and data linkage-related barriers

In the pre-roundtable survey, respondents nominated the following data, processes and data linkage-related processes as the most significant in preventing national breast cancer stage and recurrence data:

Most significant challenges/barriers (n=18) *
1. Challenges relating to structured reporting of pathology data
2. Methodological complexity relating to cancer state or recurrence data collection/analysis
3. The lack of an agreed national definition of cancer recurrence
4. Lack of routine and enduring health data linkages

* Ranked by weighted average

During the first workshop, attendees discussed and elaborated on these and several additional barriers to national breast cancer stage and recurrence data.

Structured reporting

Structured reporting was discussed, both in relation to pathology data and imaging data. While work is underway to expand and enhance the use of structured reporting of pathology data, roundtable attendees discussed the challenges faced by the PBCRs from unstructured pathology reporting given that pathology reports are a key source of cancer data for the cancer registries.

> " *I think that pathology continues to be a challenge. I think the pathologists know that synoptic reporting is probably where they need to go, but that again, is changing the cadence of the rhythm in the way that they work. I think that that's very difficult.* "

The need for structured reporting was also discussed in relation to imaging reports.

> " *[T]he reality is that registries are secondary users of those reports and clinical information…And so how do you tackle that incentive for pathologists and for radiologists to report in a way that registries want to report such that we can utilise and leverage natural language processing and machine learning technologies.* "

Attendees highlighted that when structured reporting is used, cancer registries are able to extract data from pathology reports much more easily.

> " *Synoptic reporting has been a game changer for us in being able to capture data from the pathology reports. That doesn't mean it's perfect, but it's certainly much better.* "

Other data, process and linkage-related barriers discussed by attendees included the following:

- Complexities and inconsistencies in terminology and definitions.

- Differences in what cancer data is mandatory to report across the various Australian states and territories.

- Significant time and resources are required to apply to access health data sets for research purposes.

- Most population-based cancer registries do not have access to imaging data, despite imaging data being a key source of information about breast cancer recurrence.

> " *…Recurrence really predominantly is found in radiological imaging reports. It's not necessarily put into a system that we can routinely receive…[N]one of the registries have access to medical imaging reports on a routine basis. So we don't even have that one vital piece of information that we need or that vital source. So that's really hard.* "

- Differences in what health data sets the population-based cancer registries have access to via health data linkages, hampering the analyses which may be undertaken across the different states and territories.

- Most cancer data is collected for clinical application within a treatment-related context, while the population-based cancer registries are secondary users of the data.

- Cancer registration processes in some states and territories are still largely manual in nature.

- The clinical uses of cancer data collected by health services are not uniform, leading to complexity across the system, with patient data stored in different locations and used for different purposes by various clinicians.

- Understanding of cancer stage and other clinical characteristics may evolve over time, and initial pathological conclusions may differ from the conclusions reached after additional tests and examinations.

- Differences in what health data sets the PBCRs have access to via health data linkages, hampering the insights obtainable through the linkage of data sets such as admitted patient data with information routinely collected by the registries.

- The increasing use of neoadjuvant therapies and its impact on cancer registration processes, particularly the collection of cancer stage at diagnosis.

> " *The clinical stage of the patient at diagnosis might be stage 3 and then they have neoadjuvant chemotherapy and their stage at the time they have a pathology report might be staged differently and sometimes the pathologist does or doesn't know that they've had neoadjuvant therapy if they're not necessarily part of a team or they're from somewhere where the patient's treated remotely and so that just adds…maybe an idea that you want clinical stage as well as what you can pull off the pathology reports…* "

- Differences in the approach to cancer data across public and private health services.

Key resourcing and technology-related barriers

In the pre-roundtable survey, respondents reported that the most pressing resourcing and technology-related barriers were lack of dedicated and ongoing funding to cancer registries for cancer stage and recurrence data collection/collation, the manual nature of cancer notification and registration processes, and cancer registry workforce constraints.

Resourcing constraints and disparities among the cancer registries' resourcing

During the roundtable, the substantial variation in funding provided to the various cancer registries by state and territory governments was stressed. Despite consensus among roundtable attendees that the population-based cancer registries are critical to the process of national breast cancer data collection, collation and reporting, attendees underlined the differences in funding across the registries, stressing that national cancer data is constrained by the jurisdictions with the most limited resourcing. Insecure and short-term funding, aging infrastructure, inadequate human resources and the manual nature of many registry processes are key resourcing barriers highlighted by roundtable attendees in both the pre-roundtable survey and during the roundtable.

> " *…None of us have any resources to do it and we're all pretty much cobbling together our registries on very limited resources as it is. So whilst we are really, really keen, we really need to get some support…We fight for our funding every year. Most of us have a large temporary workforce that we also employ to just keep going.*
>
> *[W]e are working on it in [name of state removed] to have a population level stage…There's no funding for it, but we're trying to juggle it.* "

Related resourcing and technology-related barriers discussed included:

- Funding disparities have meant that some cancer registries have old infrastructure and technology; there are also differences in size and FTE staff between the registries, constraining national breast cancer stage and recurrence data collection, collation and reporting.

- There is a need to address differences in the degree and quality of data provided to the cancer registries by health services. A number of attendees indicated cultural change is required across various hospitals and health services to ensure cancer data collection is valued, incentivised and prioritised as a routine activity.

- Much of the funding provided to cancer registries for stage or recurrence data capture has been short-term or project funding; the lack of enduring and ongoing funding for breast cancer stage and recurrence data capture is a significant barrier to population-level data.

- While federal, state and territory cancer policy and plans may highlight the importance of integrated cancer data, funding is not always attached to enable implementation of activities.

Key governance, legislation and policy-related barriers

Attendees characterised the legislation regarding cancer notification requirements and data access processes as a 'complex landscape'. Processes to access and use cancer data for research and other purposes are resource intensive and time consuming, with one attendee sharing that they applied to access data 3 years ago for a record linkage project and were 'still only partially in the queue to actually get the data'.

> " *I think there really does need to be a wake-up call around how we access this data and how that functions in Australia, if we really want to use this data to drive the system forward.* "

Other attendees noted that current arrangements result in duplication of effort, as research groups working on similar projects must apply separately to access the data and are constrained in what can be shared.

Other challenges discussed included:

- A crowded health policy agenda and number of challenges facing the health system makes the prioritisation of cancer stage and recurrence data by the federal, state and territory governments difficult to achieve.

- The significant time and resources required to change legislation, even if agreement is reached about the need for legislative amendment.

- Difficulties arising from the lack of national agreement regarding how 'cancer recurrence' should be defined, though several attendees noted that a definition could be developed solely for data collection purposes.

> " *[T]he definition can be just used for that legislation. It doesn't have to then apply across to clinicians… [I]t can be just simply a purpose orientated piece of legislation that defines recurrence just solely for data collection.* "

- Complexities arising from the number of different audiences and users of cancer data, which must be considered by any legislation and/or policies developed.

It's time for action ▶

We strongly encourage interested stakeholders to contact BCNA's Policy & Advocacy team for more information on our work and advocacy for metastatic breast cancer. Please email **policy@bcna.org.au** to get in touch.

Researchers conducting work related to metastatic cancer are encouraged to involve consumers early in the development of their projects. BCNA's Consumer Representative program, Seat at the Table (SATT), provides trained Consumer Representatives who work with researchers, committees and decision-making bodies throughout Australia to represent the experience and views of all people affected by breast cancer in Australia. More information can be found on our website or by contacting BCNA's Policy & Advocacy team.