

Getting it all together

Connecting Australian breast cancer care

An Economist Intelligence Unit report



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Preface

Getting it all together: Connecting Australian breast cancer care is an Economist Intelligence Unit report, sponsored by GE. The EIU conducted interviews independently and wrote the report. Elizabeth Fry was the author of the report, and David Line was the editor; Nathan Griffiths, Laura Kenworthy and Dr Paul Kielstra provided additional research and reporting. Gaddi Tam was responsible for layout. The cover design is by David Simonds.

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We would like to thank all interviewees for their time and insights.

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Executive summary

Breast cancer is the most common cancer in Australian women. The good news is that more Australian women are surviving it than ever before, and Australia ranks highly among its developed-economy peers in terms of patients' access to cutting-edge treatments, mortality rates and chances of long-term survival. Nevertheless, it also shares with other rich countries a rising incidence rate as its population ages. And although advanced in several senses, breast cancer control in Australia faces some unique challenges.

For this report, *Getting it all together: Connecting Australian breast cancer care*, the Economist Intelligence Unit interviewed a range of experts working across the breast cancer field, from research to prevention to treatment, to provide a status report on Australia's bid to eliminate the disease. Putting its efforts in an international context, the report examines what Australia is doing well, where it still faces challenges and how experts think these might be overcome. It also includes a variety of "best-practice" case studies on innovative local, national and international initiatives. The conclusion outlines what experts see as priorities in the continuing struggle against the disease.

One theme that unites the majority of findings of this paper is the importance of co-ordinating and connecting the various parts that together constitute a comprehensive national breast cancer control programme. Given the sheer number of people and institutions involved, it is not surprising that co-ordination among them is not always optimal: the "fragmentation factor" remains present in various aspects of research, funding and treatment. To be sure, Australia is among the global leaders in many aspects of its approach to tackling the disease, but improving connections—whether between the federal and state governments, the public and private health systems, NGOs and public bodies, researchers and clinicians, or cancer specialists and GPs—is a priority across the breast cancer field.

Other key findings of the report include:

- **Progress in early detection and treatment is impressive, but growing incidence demands continued focus.** Headline mortality and survival figures for breast cancer in Australia have been steadily improving. This is due to the government's commitment to evidence-based guidelines for the management of breast cancer treatment, robust funding, and a high degree of collaboration between breast cancer organisations. Internationally, Australia ranks above many of its peers in terms of incidence, mortality and screening. However, Australia's own screening goals among target



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demographics have not yet been reached, and a rising incidence rate demands continued effort to maintain progress.

- **A patient focus has led to good co-ordination between breast cancer bodies, but streamlining funding remains a challenge.** A high degree of collaboration between breast cancer organisations across the field, together with a culture of multidisciplinary care and a strong consumer focus, have helped offset the inefficiencies of a complicated health system. However, there is no overall co-ordination of funding for initiatives related to breast cancer, inhibiting long-term investment. This also makes it tougher for NGOs, some of which question the long-term sustainability of their funding obligations. Like other countries frustrated with such fragmentation, Australian NGOs are working towards a national plan to co-ordinate priorities in strategy and funding.
- **Better data co-ordination is a priority.** Putting together evidence-based programmes demands quick access to comprehensive data sets. But it is far from easy to get sufficient national figures in Australia: data collection systems are incompatible, each of the states controls its own cancer registries and data applications can take months. There are also big gaps in the information on what happens to patients once they start treatment. Cancer Australia and leading NGOs have identified unifying data as a priority; innovations from elsewhere (such as the UK's national tissue bank, the first of its kind in the world) underscore how important access to unified sources of information is for breast cancer researchers.
- **Too little attention is being paid to prevention.** Many think Australia (in common with many countries) pays too little attention overall to breast cancer prevention. This will demand increasing focus as genetic-risk profiling advances, particularly to fund follow-up studies on lifestyle and preventative intervention. The government is targeting more preventative healthcare in general, but identifying breast cancer risk factors—and communicating them effectively—remain a challenge.
- **Translating research into clinical practice and strengthening multidisciplinary care are increasingly important.** Although in its early days with regard to breast cancer, genomic research leading to personalised treatments will put a greater emphasis on translating research into clinical practice, as is happening in major cancer research centres in Canada, the UK and the US. In Australia, translational research is now on most funders' agendas, and the development of the new large cancer centres is partly to facilitate closer links between scientists and clinicians. Regarding treatment, Australia's public sector has a strong culture of multidisciplinary care, but there is scope for even greater integration of research with clinical practice, and for more aspects of treatment and post-treatment care to be co-ordinated.
- **Some population groups are doing worse than others.** As with many other diseases, breast cancer sufferers in remote and rural regions can expect worse outcomes. This is because cancer care services tend to be centralised in the cities: long travel times delay diagnosis, meaning sufferers are less likely to identify the disease early. Rural and remote communities also tend to be poorer and have greater incidence of associated lifestyle risks like smoking and obesity. Some innovative NGO-led community programmes have made headway in reaching these regions, but the problem is that the difference in breast cancer outcomes is just one of many such healthcare disparities.



Introduction: So far, so good

Breast cancer is the most common cancer in Australian women, with one in 11 developing the disease before the age of 75.¹ It is also the primary cause of female cancer deaths. The good news is that more Australian women are surviving breast cancer than ever before. Significant advances in early detection and treatment currently mean 88% of Australian women diagnosed with the disease can expect to be alive five years after diagnosis, according to the latest estimates by the Department of Health and Ageing. (This compares with around 72% for women diagnosed a generation ago.²) Survival rates rise to 97% if the disease is localised and diagnosed early.³

Along with many rich nations, Australia suffers from a relatively high incidence of breast cancer that has risen fairly steadily for much of the past 20 years (Figure 1). According to GLOBOCAN, an international cancer database, Australia reports around 85 cases per 100,000 females, placing it among the higher-ranking countries for breast cancer incidence. Mortality rates, however, compare favourably to similar countries, with Australia reporting fewer than 15 deaths per 100,000 females, below Canada and the UK, and considerably below its nearest neighbour, New Zealand (Figure 2).⁴

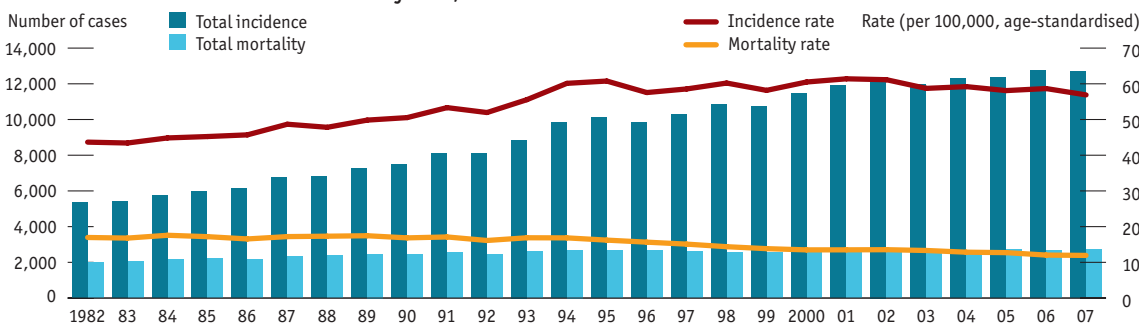
¹ Australian Institute of Health and Welfare, *Cancer in Australia, an overview, 2010*.

² National Breast Cancer Foundation (NBCF), *National Action Plan for Breast Cancer Research 2010*, October 2010.

³ Department of Health and Ageing, *Report to the Nation—Breast Cancer 2010*, October 2010.

⁴ GLOBOCAN 2008, IARC

Figure 1
Australia breast cancer incidence & mortality rates, 1982-2007



Source: AIHW, *Australian Cancer Incidence and Mortality Book, 2010*



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Figure 2
Breast cancer mortality in select countries (2008)



Source: GLOBOCAN 2008, IARC

⁵ BreastScreen Australia Program, *Screening Monograph No. 1/2009—Evaluation Final Report*, June 2009.

⁶ Department of Health and Ageing, *Breast Cancer* (undated memo).

⁷ Department of Health and Ageing, *Health Budget 2009-2010*, May 2009.

⁸ NBCF, *National Action Plan 2010*, op cit.

⁹ Canadian Cancer Research Alliance, *Cancer Research Investment in Canada, 2006*, August 2008.

¹⁰ BreastScreen Australia Program, *Evaluation Final Report*, op cit. 2008 data is used in figures 3 and 4 where possible for purposes of comparison.

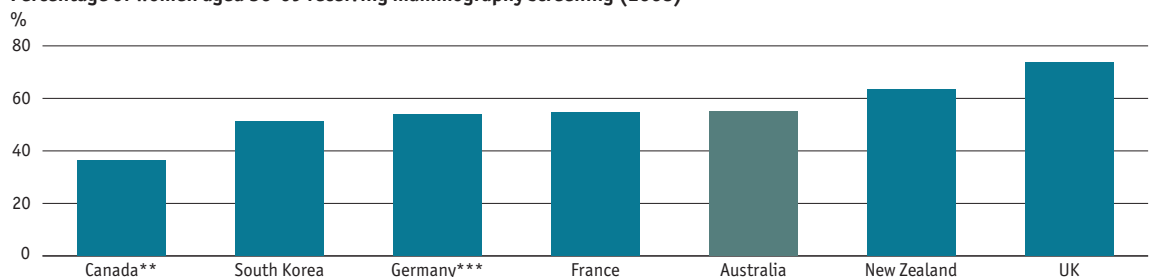
Australia has made huge strides in diagnosing and treating breast cancer as the disease has gathered increasing mainstream attention, better funding and greater support from the public, private and non-profit sectors. This is also down to early detection through widespread, government-funded screening programmes and the early adoption of new therapies. Since the introduction of BreastScreen Australia in 1991, the breast cancer death rate in women aged 50-69 years has been cut by between 21 and 28%.⁵

The solid outcomes reflect the government's commitment to evidence-based guidelines for the management of breast cancer treatment, and robust funding. For instance, since 2007 the federal government has committed A\$2.5bn (US\$2.6bn at current exchange rates) to cancer control overall.⁶ In 2010 the state governments spent A\$174.6m on BreastScreen Australia—a figure roughly matched by the federal government. And in 2009-10, A\$560m was allocated from the Health and Hospital Fund to help improve support for cancer patients in rural and regional communities.⁷

The complex and often overlapping nature of cancer funding arrangements makes it difficult to compare spending on breast cancer in an international context. It is clear that breast cancer often receives the largest share of research funds. A 2010 report from Australia's National Breast Cancer Foundation (NBCF) found that in 2005, nearly 30% of all cancer research funding in Australia focused on breast cancer. That compared with 24% percent in the US and 18% in the UK in 2006.⁸ An annual report on research funding by the Canadian Cancer Research Alliance showed that 12% of Canadian cancer research funds were spent on breast cancer in 2006.⁹

In terms of early detection and screening, Australia compares well enough internationally but is still missing its own targets. According to BreastScreen, the participation rate among the target female population is 56%, compared with a desired rate of 70%.¹⁰ According to OECD figures, New Zealand and the UK have broader screening coverage than Australia (Figure 3).

Figure 3
Percentage of women aged 50-69 receiving mammography screening (2008)



* 2004 ** 2007
Source: OECD, programme data



Figure 4: International comparison summary, select nations

Breast cancer incidence per 100,000 females (2008, age-standardised)		Breast cancer mortality per 100,000 females (2008, age-standardised)	
South Korea	38.9	South Korea	5.3
Japan	42.7	Japan	9.2
US	76.0	US	14.7
Germany	81.8	Australia	14.7
Canada	83.2	Canada	15.6
Australia	84.8	Germany	16.9
UK	89.1	France (metropolitan)	17.6
New Zealand	89.4	UK	18.6
France (metropolitan)	99.7	New Zealand	19.0
Denmark	101.1	Denmark	20.8

Source: GLOBOCAN 2008, IARC

Source: GLOBOCAN 2008, IARC

Screening rates for women in target age ranges (% , 2008)	Estimated DALYs* per 100,000 female population by breast cancer (2004)	Five-year relative breast cancer survival rate (age-standardised, %, 1999)
UK	South Korea	US
New Zealand	Japan	Canada
Australia	US	Japan
France	Australia	Australia
Germany*	Canada	France
South Korea	New Zealand	Germany
Canada**	France	Denmark
Denmark	Germany	UK
US	UK	New Zealand
Japan	Denmark	South Korea

* 2007 ** 2004

Source: OECD, programme data. Refer to OECD *Definitions, Sources and Methods* notes for further information on this data.

*Standard DALYs with age-weighting and time discounting as reported in World Health Report 2004. DALYs for a disease or health condition are calculated as the sum of the years of life lost due to premature mortality (YLL) in the population and the years lost due to disability (YLD) for incident cases of the health condition.
Source: WHO

Differences in collection and methodology between national cancer registries often impede direct comparison of survival rates.
Source: *The Lancet Oncology*, 2008; 9: 730–56. Refer to this article for further information on interpreting this data.

Australia's favourable position on breast cancer outcomes relative to its global peers (Figure 4) reflects the government's funding commitment and best practice in various aspects of Australia's breast cancer control strategy, including a high degree of collaboration between non-governmental organisations (NGOs) and a strong culture of multidisciplinary care. Never before has the disease gathered such attention, money or momentum.

However, research for this report suggests a number of ongoing challenges. And further progress will not be easy. In part because of Australia's ageing population, the incidence of breast cancer is still on the rise. By 2015, the number of new breast cancer cases among Australian women is expected to be 22% higher than in 2006 according to Cancer Australia, the national government's principal cancer-control



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¹¹ Cancer Australia, “Breast Cancer Statistics” website (updated January 2011), citing Australian Institute of Health and Welfare and National Breast and Ovarian Cancer Centre (NBOCC), *Breast cancer in Australia: an overview*, 2009.

¹² World Health Organisation, “Global cancer rates could increase by 50% to 15 million by 2020”, April 2003.

agency.¹¹ These estimates are broadly in line with global projections that suggest that the absolute number of new breast cancer cases will be among the highest of all types of cancer by 2020.¹²

Such projections underline the need for continued focus on the best ways to organise breast cancer control. Frequently, given the number of stakeholders involved and the range of treatment options, this comes down to improving co-ordination and minimising the “fragmentation factor”—whether in overall strategy, research and funding, or patients’ course of treatment. The remainder of this paper discusses where, in the opinion of experts working to combat the disease, efforts to improve co-ordination in breast cancer control should be directed.



Key points

- National guidelines focused on patients, rather than clinicians, together with strong collaboration between breast cancer organisations, has helped overcome some of the problems associated with Australia's federal bureaucracy and mixture of public and private healthcare providers. But better co-ordination of funding, in particular, is a priority.
- Better national co-ordination on data collection and sharing is necessary. Data on treatment, in particular, is either insufficient or not integrated, impeding research and the establishment of evidence-based guidelines.
- National plans for integrated healthcare records may be beneficial for breast cancer control, if they establish unified standards. But progress has been slow, and some think the cost of adopting new platforms will hinder compliance.

1. Connecting stakeholders

One barrier to the improved co-ordination of breast cancer care is the Australian healthcare system. The federal system generates problems in accountability, the duplication of costs and allocation of funds, and delays when state borders impede national healthcare decisions. In addition, the mix of public and private health systems can be problematic, as breast cancer patients frequently traverse the public and private systems for different aspects of care. Electronic medical records do not extend across the two systems, and treatment can be interrupted when patients are discharged from one system and enter the other. Unlike the UK, where the majority of health lies within the public system, Australia's private hospitals carry out a significant proportion of the surgery.

Efforts have been made to co-ordinate different organisations in delivering care, focusing on the needs of the patient. In 1995 the National Breast and Ovarian Cancer Centre (NBOCC¹³) laid down evidence-based guidelines for practitioners on the management of breast cancer treatment.

Helen Zorbas, CEO of Cancer Australia, emphasises the importance of the fact that these guidelines incorporated the experience of women with breast cancer—a significant change from the traditional clinician focus at the time. “Promoting patient-outcome measures, we worked with clinicians, researchers, hospitals and consumer organisations, ensuring that global best practice was imported into Australia,” Dr Zorbas says.

Now, the culture of patient involvement is so strong that Australia arguably represents best practice in this respect. Cancer Australia's framework for consumer involvement includes a written expectation that consumers will participate in all aspects of policy setting and research. And some research funding bodies reject proposals that omit such participation, says Lyn Swinburne, chief executive of Breast Cancer Network Australia (BCNA), a powerful lobby group with 60,000 members. “It keeps [funding] about the patient and means research is more likely to be translated into improved care on the ground.” (See case study 1.)

¹³ The NBOCC was amalgamated with Cancer Australia in June 2011.



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Case study 1: BCNA—A seat at the table

Breast Cancer Network Australia (BCNA), a 60,000-strong consumer advocacy group, actively ensures the focus of policy development, service provision and research remains squarely on the patient and translates into clinical practice. “Seat at the Table” is a BCNA initiative to attract, appoint, train and support women with breast cancer to be consumer representatives within the health system. Some of these women represent BCNA on committee boards and project teams; some review research proposals and work with researchers to develop trial protocols; others help develop and manage patient support services and generate consumer literature.

The Seat at the Table idea came from the US. The federal government there funded training programmes for breast cancer sufferers to help assess the science and set priorities. But the movement has gathered some real momentum in Australia. In the US, consumer advocacy groups do not necessarily have a government imprimatur. In Australia, however, the federal government has insisted that consumer involvement in research leads to better outcomes. Cancer Australia’s framework for consumer involvement includes a written expectation that consumers will participate in all aspects of policy setting and research.

The Seat at the Table programme in Australia delivers highly knowledgeable and committed consumer representatives. “We identify someone who can sit down with the rest of the members of

the team—health professionals and researchers—and represent the view of the people who might use the service,” says Lyn Swinburne, chief executive of the BCNA. Network members are screened and entered into an internal database. This way, the Network is better able to identify the right person for a particular trial.

Training is then provided by the BCNA over a three-day period. Without being expected to be scientists, its members have to be familiar with terms being discussed. The women must also be able to assess the benefits of a particular trial but withhold approval until all their questions about what that trial means for patients have been answered in full.

“The programmes give them confidence, basic skills and knowledge as well as a clear idea about how best to represent other cancer sufferers”, says Ms Swinburne. “The women in our network have read every medical journal known to man and follow the science closely.”

The women who elect to join the BCNA research programme check that research topics are not being duplicated elsewhere, or that researchers do not become overly focused on issues only tangential to the clinical outcomes at the top of patients’ minds. Conversely, the BCNA has at times given support to studies that address novel ideas, but whose researchers might lack a long list of published research and might therefore struggle to attract funding through other sources.

“Women who act as consumer representatives or advocates have no particular vested interests,” says Ms Swinburne. “They’re not working to develop someone’s scientific career.”

Outside these guidelines, a high degree of collaboration among NGOs—as well as between the NGOs and the federal government—has helped offset the inefficiencies of a dual health system. There is a clear delineation of roles in various breast cancer organisations. Each body fills a niche and an area of need for patients. Cancer Australia’s role, for instance, is to provide overall co-ordination and set clinical guidelines, while BCNA champions patient advocacy and the NBCF raises money for research. The McGrath Foundation, meanwhile, funds breast care nurses in communities across Australia and helps to increase breast cancer awareness in young women (see case study 7, below). These groups operate internationally through partner associations.

For 15 years, the leading cancer bodies have co-ordinated their activities to focus on research, clinical practice and patient advocacy. “From a policy point of view there were very clear messages being sent to healthcare providers and politicians,” says Kylea Tink, CEO of the McGrath Foundation.

Ostensibly there is an easy collaboration among the groups. “The chief executives and the chairs regularly meet to update each other, discuss challenges and how we can help each other overcome them,” Ms Swinburne says. “We recognise we are all out for the same thing, which is to improve outcomes for women; the fact that we can sit down and talk says a lot.”



Clarifying funding

However, collaboration is not always as straightforward when it comes to funding. This is partly because there is no clear picture of expenditure on cancer research and control in Australia. Building a complete and up-to-date picture of federal government and state funding on specific cancers, for instance, is impossible, since schemes that subsidise the cost of hospitals, cancer treatments and research overlap.

Currently, funding is supplied from state and federal governments, NGOs and a handful of charities and councils. Extra money comes from trusts, philanthropic initiatives and the private sector, including the pharmaceutical industry. Importantly, there is no co-ordination for breast cancer research funding or, indeed, for any other cancer, and the lack of a single source of data inhibits investment in breast cancer research. Funding agencies are reluctant to publicly report funding, making it hard to check the value of research.

The situation also makes it tougher for some NGOs that see their funding obligations stretch out indefinitely. According to Carole Renouf, CEO of the NBCF, the Foundation has granted funds to some projects over a number of years but is currently deliberating when enough is enough. “How ongoing can ongoing funding be?” she asks. “Is it the right thing for a non-profit organisation to fund [projects] in perpetuity?”

To be sure, Australia’s lack of co-ordinated funding patterns is not unusual. Breast cancer research funding in the US is split between federal agencies, state and local governments, voluntary organisations, private institutions and industry, without a centralised overview being taken. (The National Cancer Institute, however, is the principal agency for cancer research and co-ordinates the National Cancer Program, within which breast cancer is included.)

In the UK, while certain organisations fund specific areas of research, the choice for a scientist of where to apply for funds for a particular project is a fairly arbitrary one. The lack of co-ordination means funding for some aspects of breast cancer research get insufficient attention, some say.

“The thing that really demonstrates the poor co-ordination of our funding system is the poor funding of preventative research,” says Gareth Evans, consultant in clinical genetics at St Mary’s Hospital, Manchester, and a member of the scientific advisory board for Breast Cancer Campaign, a UK charity. “It receives a minute proportion of the funds available, whereas if anyone was taking a strategic overview of the whole thing, it would be obvious that it’s an area that needs to be invested in.”

Canada, by contrast, has long sought to synchronise breast cancer research funding—even though cancer care itself is organised and delivered at a provincial rather than a national level. The Canadian Breast Cancer Research Alliance (CBCRA) was formed in 1993 with the specific intention of co-ordinating efforts across the country to reduce potential duplication and maximise impact.

In 2010 the CBCRA released the National Breast Cancer Research Framework, intended to serve as a reference point for the future co-ordination of efforts around shared priorities. The Framework is currently being put into action through the creation of the Canadian Breast Cancer Research Collaborative, which will co-ordinate research funding between the country’s various government, NGO and charity research funding organisations.

Australia’s NGOs are also working to develop a national plan for cancer research for Australia to



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identify the funding gaps, neglected areas and work out how they can better pool resources. Slated for completion in mid-2013, this integrated plan will play a big role in determining where NGOs put their funds.

“We’ve long been concerned about the fragmentation of the cancer research non-profit sector, and we’re keen to drive collaboration and consolidation,” says Ms Renouf of the NBCF. “While none of us believe the plan will be a panacea for all ills, analysis of existing state, national and international cancer plans and conducting consumer consultation will confirm where we all might best direct our funding efforts.”

Sharing data

The paucity of reliable information goes beyond how much money is available: problems with data on treatments and outcomes—vital for developing evidence-based cancer control strategies—illustrate the need for better national co-ordination.

Currently each of the states controls its own cancer registries and, under strict conditions, will provide data to the national health statistician. Anyone else who wants to examine national data has to apply to an ethics committee in each state, which takes months. It can also be difficult obtaining Medicare data for research. Added to that, there are issues related to whether the states or federal government controls access to state-based BreastScreen data.

“Many of the arguments for restricting data access and linkage are predicated on privacy issues, but often this is tenuous,” says Ian Olver, CEO of Cancer Council Australia, the nation’s leading non-governmental cancer control organisation.

Worse, there are big gaps in the information between what happens to the patient once they start treatment. According to Dr Zorbas: “We know about cancer incidence, how many people died and how long they lived with the disease, but we don’t know much about what happens in between. We don’t capture, at a national level, what happens to the patient once they start treatment and link that to registry data.”

This information is available in pockets but is jealously guarded by its custodians. Moreover, the systems are not integrated. Linking those data sets is an important challenge, as it has to be done in a way that is secure and does not affect the data sets that do exist. “It’s extraordinarily complex because the data are not recorded uniformly; the systems won’t talk to one another and in some instances are not mandated to capture the data,” says Dr Zorbas.

Without such data it is really not possible to determine whether women are receiving the best available treatment, among many other important issues. It also could impede further research into genetic risk factors, which depends on the availability of large data sets that contain relevant individual data, including physiological and genomic information.

In the UK, the creation of ever more high-functioning and reliable databases, allowing far greater storage, sharing and comparison of research, has had a significant impact on breast cancer treatment. “The difference that has made has been absolutely crucial,” says Professor Evans. Its efforts to promote national collaboration between researchers on other issues—such as a groundbreaking tissue bank (see case study 2)—underline the importance of unified sources of data.

In Australia, the federal government has acknowledged the need to address these issues. But any



solution involves negotiating with state jurisdictions as well. Since Cancer Australia has responsibility for cancer planning throughout the country, many think it should sort out the breast cancer data sets that are needed for both planning and research activities.

Case study 2: The UK Tissue Bank

The existence of the National Health Service (NHS) in the UK would suggest researchers and clinicians within the country would have no problem sharing and accessing information on breast cancer. But this has not always been the case. In 2006 the charity Breast Cancer Campaign decided to fund an exercise looking at the barriers to promoting more successful research, explains Baroness Delyth Morgan, the charity's chief executive. "Our gap analysis brought leading scientists together, and lack of access to tissue was identified as a key barrier."

The priority, when removing cancerous tissue from a patient, will always be to establish an accurate diagnosis. But excess tissue, which would otherwise be incinerated, is an enormously valuable learning tool—the donation of which demands nothing but consent from the patient.

As a result of its study, Breast Cancer Campaign funded the development of the Tissue Bank, the world's first national approach to the need for scientists and doctors to have ready access to breast cancer tissue. Consistently stored and annotated samples will be available from 2012 to researchers throughout the country through

a single web-based portal, thanks to collaboration between the University of Dundee/NHS Tayside, the University of Nottingham, the University of Leeds, and The Barts Cancer Institute at Queen Mary University of London.

"Before we developed the Bank, individual scientists or pathologists might develop their own collections of tissue, but it wasn't systematic, and it wasn't making the best use of the NHS as a national organisation," says Baroness Morgan. "The scientists we spoke to emphasised the importance of access to different kinds of tumours; of understanding the response to different treatments; what happens in metastatic breast cancer; what secondaries look like; and what markers you might find in blood. We've been able to build a critical mass of samples so that all these questions can be explored."

Louise Jones, professor of breast pathology at Barts and the London NHS Trust, emphasises the importance of national collaboration on the issue. "Until now, it's been pure luck whether a particular scientist has access to cancer tissue sample—it's been down to who they know. We wanted to take that element of luck out of it. As a pathologist I've been involved with tissue for a long time, so I'm aware of the enormous research value it has. Not to be able to harness that seems outrageous."

Rolling out IT

Broader plans for e-health investment have the potential to help address various challenges in breast cancer control, especially if they can improve the exchange of data between public and private institutions, and between specialists and GPs—thereby reducing the "fragmentation factor" that concerns many breast cancer patients.

"Because breast cancer is treated by multidisciplinary teams, to have an electronic record instantly accessible to team members will be particularly useful," says Professor Olver. "In fact, [e-health] ... is essential for good co-ordinated care."

However, progress on this front has been slow, and many think Australia lags its global peers on rolling out healthcare IT on a national scale—even if there are plenty of pockets of innovation at well-funded university medical centres or clinics.

Nevertheless, the idea of national, personally controlled electronic health records (PCEHRs) is gaining momentum, and the government is committed to pressing ahead. In August 2011 the National



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E-Health Transition Authority, set up in 2005, outlined a national standard for the way in which patient records are to be stored and then theoretically shared—once the security parameters are put in place. Canberra is also investing A\$470m from July 2012 to introduce e-health across the country and to help the software industry comply with that new standard.¹⁴

Whether or not this will lead to widespread compliance is not yet clear. Physicians may still be reluctant to switch to the new technology, amid concerns about sharing patient information and the possibility of patients tampering with their own records. Moreover, industry insiders say few software companies are yet able to comply with the standard because of the cost associated with accommodating the new platform across all licensees and sites. Most are looking for government guarantees that compliance costs will be covered.

Regardless, the new system will bring benefits for breast cancer control, as the standard allows for the inclusion of pathology and diagnostic imaging results, discharge summaries, and information on medications dispensed.

John Boyages, director of the Westmead Breast Cancer Institute in western Sydney, sees great potential for improving screening coverage in particular. “The digital revolution means that we can perform BreastScreen-accredited X-rays anywhere, including in private practice, public hospitals, and mobile vans, and get them transferred via the Internet to accredited reading centres,” he says.

Such systems may eventually help the drive to collect better data for national breast cancer registries. While promoting PCEHRs is principally about individual care, in future such records may be able to feed in automatically to national datasets, providing comprehensive and timely information on treatment efficacy and risk factors. Such plans are, as yet, in the distant future, but the prospect for better IT connections across the healthcare system is an enticing one for the future of breast cancer control in Australia.

¹⁴ Minister for Health and Ageing, *E-Health Conference—Revolutionising Australia's Health Care*, October 2010.



Key points

- Australia—like many countries—pays less attention to prevention in its breast cancer control strategy than to early detection and treatment. Preventative research is increasingly important as genetic-risk profiling advances. The government is targeting more preventative healthcare in general, but identifying breast cancer risk factors—and communicating them effectively—remains a challenge.
- Connecting research and treatment will become increasingly important with the development of personalised treatments. Progress on this front for breast cancer has been slow, but Australia is part of an international effort to close the gap between discovery and application.
- Multidisciplinary care has long been international best practice in breast cancer treatment and is robust in Australian public healthcare. Personalised treatments will make co-ordination even more important. As in many other countries, connections between cancer specialists and general practitioners (GPs) could be improved.

2. Connecting care across the continuum

Targeting prevention

Despite the relatively high profile breast cancer has received in recent years, and the diagnostic research carried out on women who are at the most risk of developing cancer, many think there is still insufficient focus on prevention. Only 5% of funds across all types of cancer research were allocated to prevention in the period 2003–05, according to Cancer Australia’s 2007 audit. The NBCF says it contributed 8% of its funds to prevention during this time, mentioning that national research bodies in the US and the UK also spent similar proportions.¹⁵

Jim Bishop, formerly Australia’s chief medical officer and the inaugural executive director of the Victorian Comprehensive Cancer Centre (a joint venture bringing together eight leading cancer hospitals and research bodies), acknowledges that it is a global issue. But he says it is “not so much a case of funding but rather of building up research capacity and better methods of research in this area.”

Prevention research covers a number of issues, including the critical one of risk profiling. Here, genomic research is increasingly important, says Professor Bishop. “We are identifying people most at risk based on their genetic makeup. This provides a clinical pathway to either prevent the disease or at least mitigate it through surveillance.”

With his colleagues at the University of Melbourne, John Hopper, a genetic epidemiologist, has been carrying out a nationwide study of high-risk families to track down genes associated with increased breast cancer risk, as well as a population-based study to determine the prevalence and actual risk that such genes confer. Bringing the two studies together was a way of getting definitive data on the twin roles of genetics and lifestyle.

Yet Professor Hopper is concerned that too little funding goes into prevention research. He cites a programme led by Associate Professor Kelly Phillips at the Peter MacCallum Cancer Centre that discovered that some women at high genetic risk could cut their risk if they took the anti-cancer tablet,

¹⁵ NBCF, *National Action Plan 2010*, op cit.



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Tamoxifen. Professor Hopper and his team have also published work suggesting, controversially, that women who carry high-risk mutations in the gene BRCA1 could be at much lower risk of breast and ovarian cancers if they take the oral contraceptive pill.

These and other potential avenues of “lifestyle-related” risk reduction for women at high genetic risk need much further research, including long-term follow-up studies of families with breast cancer. “What is the point of a women knowing she is at a high risk of breast cancer if we can’t prevent it?”, he asks.

Together with genetic-risk profiling, there is a renewed national emphasis on primary prevention. In 2010 the federal government’s new Preventative Health Taskforce put forward a plan that will hopefully translate into a more preventative public health policy, after an analysis of drug subsidies showed 18 of the 50 most-expensive pharmaceuticals treat diseases that are often preventable, such as those associated with poor diet, obesity and smoking.¹⁶ Establishing the taskforce is timely. “Now that we are getting a better handle on the genetics, we need funding to continue our long-term family studies of lifestyle to find proven means for preventing cancers in high-risk women,” Professor Hopper says.

The trick is identifying which lifestyle angle to focus on. According to Ms Renouf, “the greatest limitation to prevention research at this point in time is the identification of new targets for prevention. Once targets are identified research usually follows fairly quickly, especially if the targets involve some type of drug.” Professor Bishop agrees: “Lifestyle studies, combined with genomics, have already produced outcomes. The more this influences practice, funding will occur organically since it will be the most cost-effective treatment.”

Indeed, there are a number of studies that focus on exercise and nutrition as opportunities for prevention. Some exercise intervention research is being conducted in both Queensland and New South Wales (NSW), with a focus on examining reductions in breast cancer recurrence.¹⁷ There is little research as yet examining the role of alcohol in breast cancer development and recurrence. This may be an avenue for future prevention research, although there is no universal agreement on the importance of alcohol with regards to breast cancer.

“It has been difficult for prevention researchers to get exercise and nutrition intervention studies funded as they typically require large numbers of subjects and require many years of follow-up—this is an issue internationally,” says Ms Renouf.

Even where risk factors are established, it does not automatically follow that they are widely acknowledged. Surveys examining what women know about breast cancer continue to reveal major gaps in their understanding of the disease and what they can do to reduce their risk. This suggests that some type of ongoing social marketing initiative is needed that is tailored to specific high-risk populations. A few years ago the NBOCC developed an online breast cancer risk assessment tool that allowed women to identify actions to reduce their risk of breast cancer. But more research into this area is needed given the results of recent knowledge and attitude surveys.

Ms Renouf sums up the problem: “One of the major challenges in breast cancer prevention research is that we have little understanding of how to effectively communicate breast cancer risk in a manner that women can understand, and which results in their taking actions to reduce their risks of developing the disease.”

¹⁶ Mannheim, M, “Lifestyles weigh on PBS”, *Canberra Times*, August 2011.

¹⁷ Australian Cancer Survivorship Centre, *Current Survivorship Research*, 2010.



Translating research into treatment

Despite the major advances in breast cancer research over the past 20 years, the process whereby breakthrough discoveries are converted into clinical treatment remains inefficient. This situation has led to an emphasis on “translational research” to close the gap between research and clinical applications. These efforts have been fuelled in recent years by the move towards personalised medicine through genetic testing. Responsiveness to treatment—whether drugs, radiation or surgery—depends very much on the patient’s genome and the mutations driving the cancer.

However, there are challenges ahead. Most genetic information does not give clear-cut answers. Much will rest on Australia’s ability to assess and judge the risk of breast cancer in different individuals, and

Case study 3: Helping everyone to WIN

It has long been clear that, rather than a single disease, cancer is actually a family of similarly symptomatic diseases caused by different genetic mutations. Accordingly, a growing number of treatments have appeared that target patients who have specific genetic markers. The problem is, however, that progress in this field is painfully slow. Just a handful of biomarkers are discovered every year and in the past decade only one, HER2, has affected treatment. This lack of clinically useful biomarkers also slows down diagnosis, which has a direct effect on outcomes.

The Worldwide Innovative Networking (WIN) Consortium was founded in September 2010 to speed up research into this personalised approach. WIN, originally an initiative of the Institut Gustave Roussy near Paris and the University of Texas MD Anderson Cancer Center, brings together 17 academic centres worldwide, three technology companies, and two patient groups in collaboration. The goal is to take discoveries from the field of personalised medicine and translate them into items of clinical utility.

In practice this means supporting a handful of trials each year that benefit from collaboration across member organisations of the consortium. By tapping into a wide variety of partners around the world, which have access to a highly diverse range of populations, the goal is that WIN trials will be completed in three to five years, much quicker than typical industry clinical trials. The intent is that where the results are positive, partner pharmaceutical and technology companies can develop products useful for cancer healthcare. Vladimir Lazar, chief operating officer of WIN, reports that the consortium’s global reach, the expertise of those involved, and the operating model have already attracted the attention of

several major pharmaceutical companies.

Although exciting for cancer research in general, this initiative may seem no more related to breast cancer treatment than to that of any other type of cancer. However, breast cancer research and WIN are closely intertwined. This begins on an institutional level. Dr Lazar explains that “breast cancer is of major interest for all partners of the consortium.” A number of the academic centres in WIN are heavily involved in researching and treating the disease, including Gustave Roussy, which has an innovative one-day diagnosis unit, and the MD Anderson Center, which has a pioneering breast cancer clinic.

Moreover, one of the original members of WIN is America’s National Breast Cancer Foundation and the latter’s founder, Janelle Hail, is a member of the consortium’s board. The interests of the two organisations align in a number of ways. Dr Lazar says that Ms Hail “supports more than anyone else WIN’s goal to bring scientific discoveries to the bed of patients quicker, and her outstanding contribution is to remind us that early diagnosis remains the best care that doctors can provide to their patients”.

An even more important connection between breast cancer research and the work of WIN is that the former has actually provided much of the intellectual underpinning for the latter. “Breast cancer is the model,” explains Dr Lazar. “Because of breast cancer, we understand how to fight cancer.”

In particular, he notes, breast cancer treatment has been extremely important in the development of a number of core elements of modern oncology, such as the use of biopsies, echograms, and radiograms and the finding of genetic markers. “Breast cancer is where there is most accumulation of knowledge,” Dr Lazar says. “Research into it is always pioneering. What was achieved in breast cancer is now spreading to the treatment of other cancers.”



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its abilities to prevent the disease. That is why the link between research and treatment is becoming more critical. International initiatives such as the WIN Consortium, established in 2010, are helping speed up the identification of genetic markers that should help target populations at risk (see case study 3).

“We have to ensure that all the new information coming out of the genome revolution [that has relevance] is introduced into the clinical decision-making,” says Professor Bishop. “New information showing there is a gene doesn’t necessarily mean it’s relevant. Changing practice based on the presence of a gene takes hard evidence and a lot of clinical investigation.”

Increasingly this is an international effort. Australia is part of the global genome sequencing to discover what genes are associated with breast cancer. Progress towards personalised care as a result of genomic research is advancing relatively slowly in the case of breast cancer, particularly by comparison with lung and bowel cancer, for which individually tailored therapies are now possible.

“There’s been a lot of hype around it, but there’s currently no licensed breast cancer drug as a result of genomic testing, although we have seen some good results in trials,” explains Professor Evans of Breast Cancer Campaign in the UK. “Also, if you were to prescribe a drug on the basis of a patient’s genetic profile, you’d have to test the individual before treating them, which not only costs a lot of money but would also significantly delay their treatment. We [in the UK] are moving towards more tailored treatment, but we’re not there yet.”

In the US, genomic information has already helped to shape the development of breast cancer treatments such as trastuzumab (Herceptin), which works only on patients whose tumours fit a certain genetic profile. The information generated by cancer genomics projects seems likely to drive research to develop similar treatment strategies.

“Cancer is a disease of the genome, and as more is learned about cancer tumours, the more we are finding that each tumour has its own set of genetic changes,” says Linda Perrett of the US National Cancer Institute. “Understanding the genetic changes that are in cancer cells is leading to more effective treatment strategies that are tailored to the genetic profile of each patient’s cancer.”

Canada, similarly, has made significant investments in genomics and other areas, in recognition of the future prospect of personalised medicine. Currently, genetic screening facilities are available at tertiary care centres across Canada, which are usually attached to research facilities in major cities. Patients’ risk levels are already regularly evaluated through genetic testing, and molecular pathology is increasingly performed post-diagnosis to determine an appropriate treatment strategy. Molecular Pathology Centres, where tumours can be immediately analysed following diagnosis to allow the development of a personalised treatment path, are just beginning to appear in major research centres—the latest is due to open at the Jewish General Hospital in Montreal in 2012.

Australia is also making an effort to close the gap between research and treatment. Translational research is now on most funders’ agendas, and the development of the new large cancer centres, especially those in Victoria and NSW, is partly to facilitate closer links between scientists and clinicians.

According to John Shine, executive director of the Garvan Institute of Medical Research, there has been an enormous explosion of fundamental knowledge about what causes cancer and new ways to treat it. “What we are involved in is closer than ever to a real clinical application,” he says. (See case study 4.)



Case study 4: The Kinghorn Cancer Centre

The Kinghorn Cancer Centre in Sydney is a joint effort between a major hospital (St Vincent's) and a pioneering research centre (the Garvan Institute of Medical Research) to bring research and clinicians together on a day-to-day basis to improve delivery of personalised cancer care.

The union of research and clinical practice is not itself a novel idea. Research institutes worldwide are fostering relationships with major teaching hospitals so that clinical challenges can directly drive research and research can feed back into treatment. But the emphasis has changed in recent years. Speeding up the process of being able to tailor each patient's treatment to the genetic nature of their tumour has moved from being a new technology to a game changer.

According to John Shine, executive director of the Garvan Institute, to build a centre like Kinghorn from scratch expressly for collaboration between researchers and clinicians is an acknowledgement of the significance of this new worldwide focus. "Kinghorn will speed up research and bring new advances in cancer care into clinical use. Everyone wants to do it. That's where the

future lies," he says.

According to Professor Shine, this intense need to collaborate is a direct result of the mapping of the human genome. "It used to take more than a decade for breakthrough research to result in new treatment," he notes. That timeline has altered with the human genome database and new genetic technologies. "Research institutes around the world are trying to work closer and closer with hospitals to get the latest results into clinics and the clinical questions back to the lab," he says.

Professor Shine adds that the benefits of genomics, as personalised medicine, have already appeared and will soon be routine. Although the technology is expensive, the cost of DNA sequencing is dropping fast and may soon be more cost effective than conventional imaging techniques. "Every cancer centre will pick up these targeted therapies and they will become part of normal care."

His team has already added to the global research by showing that a molecule known as 'hedgehog' mutates into a nasty form of breast cancer. "We've identified a drug that inhibits this particular gene in mice and models. Kinghorn aims to take that sort of discovery into the clinic."

Strengthening multidisciplinary care

Breast cancer control is often complicated by the sheer number of organisations and disciplines involved, from research to screening to diagnosis to treatment. Where more elements of the breast cancer field can take place in co-ordination, or under the same roof, care improves. Although this has long been viewed as international best practice, it is becoming increasingly important as innovations in personalised treatment require a multidisciplinary approach that links research, more-precise diagnosis and treatment of tumours—as well as psychosocial care for sufferers and survivors.

Since the 1990s the British National Health Service (NHS) has viewed multidisciplinary care as best practice in breast cancer care, as well as in the treatment of other cancers. The National Institute for Health and Clinical Excellence (NICE) guidelines currently stipulate that all cancer patients should receive this form of care.

In the UK system, breast cancer patients are routinely cared for by a multidisciplinary team consisting of a specialist cancer surgeon, an oncologist, a radiologist, a pathologist, a radiographer, a reconstructive surgeon and a specialist nurse. Physiotherapists, dieticians and occupational therapists may also form part of the team.

"The set-up means that it's always a team decision what the best options are for a particular patient," says Professor Evans. "There is no doubt that the formation of specialist breast clinics has hugely improved outcomes."



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In Australia's public sector, the culture of multidisciplinary clinics is strong. Most public cancer centres take a team approach to reviewing individual cases, conducting diagnoses and tailoring treatments accordingly. Many public hospitals are redoubling their efforts to put research, screening and treatment under one roof.

The Melbourne-based Peter MacCallum Institute for Cancer Research, Australia's only public hospital solely dedicated to cancer treatment, research and education, is one such example. Peter Mac, as it is known, is now planning to team up with some parts of Melbourne Health (a major public health provider in Victoria) and the University of Melbourne so that cancer patients can receive all the treatment they need on one site.

This government-funded A\$1bn development also reflects the evolution towards more personalised cancer treatment, linked to genomic testing. In this way Australia is following the approach taken by the world's top comprehensive cancer centres such as the Royal Marsden Hospital in London, the Memorial Sloan Kettering Cancer Center in New York and the Princess Margaret Hospital in Toronto.

However, Australia is still a way from being able to offer full-service care to all breast cancer patients. In part this is down to geographic and administrative factors that are not unique to the country. In Canada, for example, which organises cancer care on a provincial level, while the movement towards

Case study 5: Westmead Hospital

A radiation oncologist and breast-cancer specialist since 1983, John Boyages is a big believer in a single breast cancer programme. At Westmead, together with screening and diagnosis, a reconstructive surgeon, radiologist, oncologist, medical geneticist, psychologist and breast cancer care nurses all work under one roof. The centre has a single governance structure, including an advisory board, an expert clinical advisory panel and management and staff who view breast cancer care as one service. Consequently, the model is wholly about patient care. Imaging, for example, is located next to the clinics so patients are screened and treated at one place.

Co-ordinating teams in separate silos was not easy. Getting a one-stop shop took "a lot of hours of negotiating and [caused] lots of grey hair", says Professor Boyages. He thinks the Westmead model is far from commonplace in Australia, given the complicated logistics, disagreements over the correct multidisciplinary care model and what the term means to different people.

"What proportion of hospital patients are seen pre-operatively by the core team in public hospitals?", he asks. "The core team might [usually] discuss cases by phone or it might meet once a fortnight. At Westmead, the core team meets three times a week. Once a patient is diagnosed we talk to them pre-operatively and ensure the right treatment for the right patient."

The organisational innovation is not just on-site. Professor

Boyages's bid to promote screening and treatment prompted him to build clinics in major department stores. Once a woman is screened, those images are uploaded and reviewed by Westmead's multidisciplinary medical team. "Putting clinics in lingerie departments in itself isn't new," he says. "The difference is that when the women return to the clinic they are treated by the same team, and that is unique."

At the heart of his philosophy is the idea that separate funding for screening and treatment does not work. Currently, screening and treatment are often separate programmes. Running breast cancer services the way he does at Westmead means using one budget across multiple programmes. "It's hard work to configure it because you are changing a system that is not amenable to change," he says.

In Professor Boyages' experience, the managers of screening budgets focused more on targets than survival rates, and those administering the treatment budgets could not influence the quality and patient focus of diagnostic mammography and ultrasound. "Diagnostic mammography was a small blip in an imaging department's focus," he says. "We turned this around in Western Sydney so the one programme focused on all women at risk or with a diagnosis of breast cancer, irrespective of how their cancer was first detected. It's about bringing together the pieces of the puzzle."

"Most private radiology practices are now doing great work," he adds. "It's about time [that] women can access screening mammography at any private practice that is accredited, with the films being centrally read in a centre such as ours or at the NSW Cancer Institute."



multidisciplinary care within dedicated breast cancer centres is a growing trend, it has not been established as an obligatory standard of care. At present, it is generally offered where the capabilities of major tertiary care centres permit it—most commonly in those centres associated with research institutes.

In Australia, those who have tried to create “one-stop shops” for breast cancer care say it is far from an easy task, given the number of stakeholders involved. John Boyages, director of the Westmead Breast Cancer Institute, has worked for 15 years to develop screening and diagnostic centres and has linked eight of these to a comprehensive breast cancer treatment programme in Sydney’s western suburbs. He says that because of the investment in cancer centres in the area, the development of a community-based breast cancer programme, and early detection and treatment by multidisciplinary teams, death rates from breast cancer in Greater Western Sydney dropped by 35% from 1992 (pre-screening) to 2005, the highest reduction in NSW (see case study 5).

Extending care beyond treatment

The need to better connect all stakeholders and the overarching focus on patients’ needs means there is a renewed drive in Australia that oncology treatments are carried out in alignment with other practices.

Cancer Australia says it is investigating new service-delivery models that provide the option of having follow-up care shared between the cancer specialist and the GP. The reason, the agency says, is that shared follow up supports “whole-person care and optimal use of Australia’s highly specialised work force”.

Such collaboration might also combat the difficulty cancer specialists and GPs seem to have in sharing information: electronic medical records, for example, lack input from both parties. This disconnect, Ms Renouf says, although far from unique to Australia, profoundly affects care after the cancer treatment has been completed.

As women survive breast cancer longer and longer, the emphasis on extending care beyond the treatment phase becomes more pronounced. Breast cancer becomes almost a chronic disease, giving patients other issues to deal with. The effects of treatment might stay with these women for the rest of their lives. The risk of their developing secondary cancer will be higher, for example, and some treatments will put them at greater risk of heart disease or osteoporosis.

This group of patients will therefore require specific attention, different research and different kinds of resources. It might require community care or hospital care rather than specialist care. At the same time, underlying the trial is an agreement between the specialist and the GP that allows the patient to have rapid access to the specialist, if required.

According to Dr Zorbas, “this trial [involving the GP] demonstrates a model of care to suit the increasing numbers of women who are living with this disease.” The AIHW estimated that in 2006 there were 143,967 women alive in Australia who had been diagnosed with breast cancer at some point in the previous 25 years.¹⁸

Cancer care has long included psychosocial care for sufferers and survivors. Australia took the lead on this internationally when the NBOCC developed the first psychosocial guidelines for women with breast cancer, and subsequently the first guidelines for psychosocial care for all adults with cancer. Such

¹⁸ *Breast cancer in Australia: an overview*, 2009, op cit.



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multidisciplinary care is now a cornerstone of nearly every cancer treatment plan across the world, but at the time it was quite a stretch to give equal validity to the importance of the psychosocial issues, Dr Zorbas says.

More remains to be done on this front. The NBOCC developed a tool to help assess women with breast cancer to determine if they were at increased risk of anxiety or distress. However, it has not been uniformly adopted. “Where it is used as part of routine care it has become an effective way of flagging patients who could benefit from additional support and psychological intervention,” Dr Zorbas says.

Given high levels of psychosocial morbidity amongst women with breast cancer and their partners, Ms Swinburne of the BCNA thinks Australia needs a national screening programme to identify women at psychological risk, and then to have appropriate pathways for referral for help. “A small percentage [of women] would benefit from psychological intervention from a psychiatrist; another group may well benefit from a psychologist or counsellor; many others could be helped by a peer-support group or by being able to share their experiences with other survivors,” Ms Swinburne says.

Ms Renouf agrees, pointing out that survivorship research should be tied to clinical practice. “[P]sychosocial interventions that help women post-treatment improve their quality of life need to get into routine clinical practice,” she says. “This can, and should, occur in the large cancer centres but also needs to occur in the smaller regional centres.”



Key points

- There are disparities in breast cancer outcomes and treatments in different communities across Australia. This partly reflects geographical remoteness, partly higher lifestyle-related risks in these communities, and partly lower participation in screening and research programmes by women in these communities.
- Many efforts have been made to close the gap, with various training programmes and increased government spending on rural cancer treatment and support. Breast cancer nurses that help patients navigate treatment may improve access for rural communities, as schemes in Australia and Canada have shown.

3. Connecting care across the country

A vital part of breast cancer control is ensuring that every woman in Australia can access the same quality of care. Currently this is not the case. There are well-recognised disparities in cancer outcomes in Australia that reflect the gap in living conditions and quality of life across its various populations. One of the most obvious reflects the country’s geography. Australia has vast solitary spaces, remote communities with sparse populations and an arid environment. For a range of medical issues, remoteness often equates with worse outcomes.

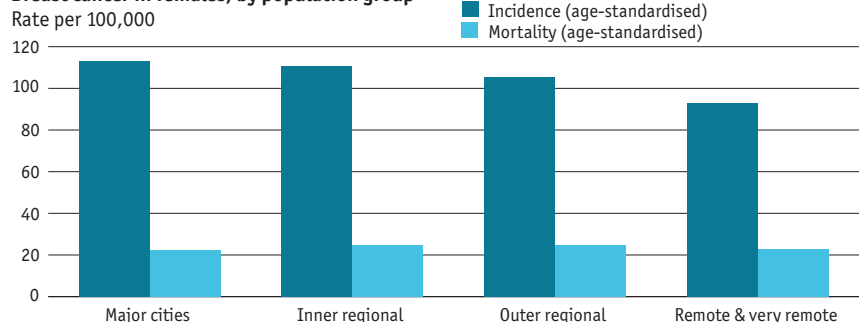
A 2004 report in the *Medical Journal of Australia* claimed that people with cancer in remote areas were 35% more likely to die within five years of diagnosis than people in cities—and for some cancers they were up to three times more likely to die in that time. This is because cancer care services tend to be centralised in the cities, and people in rural communities are forced to travel great distances to find the support and care they need, delaying diagnosis. The National Rural Health Alliance estimates that around 30% of cancer sufferers live outside Australia’s main cities.¹⁹

¹⁹ National Rural Health Alliance, *Fact Sheet 8: Cancer in rural Australia*, May 2009.

Recent official statistics on incidence and mortality (Figure 5) do not show any significant disparities in breast cancer outcomes according to remoteness (incidence rates in fact are lower in non-urban regions). But experts suggest that worse outcomes for cancer in general are linked to lifestyle choices among lower-income families in Australia, a high percentage of whom live away from the major cities.

“Compared to their urban counterparts, the risk of cancer is even higher because of lifestyle choices,” says Professor Olver of Cancer Council

Figure 5
Breast cancer in females, by population group



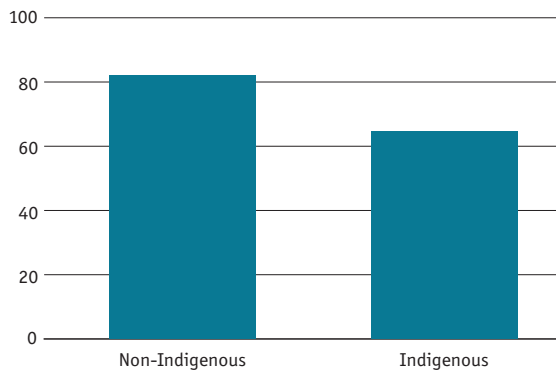
NB: Rates are based on the total number of cases over the five-year period from 2003–2007
Source: AIHW, *Cancer in Australia: an overview*, 2010



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Figure 6
Breast cancer five-year survival rate, by population type
Crude survival rate (% , NT, QLD and WA, 2002-06)



Source: NB00C, *Report to the Nation*, 2010

Australia. “This group is more likely to smoke—28% versus 11%—and more likely to be obese—66% versus 56%. They are 20% less likely to receive chemotherapy and 9% less likely to receive radiotherapy.”²⁰ Differences in survival rates vary between tumour types and depend on the degree of remoteness, he adds.

The problem is not just one of survival but also affects treatment choices, since these are determined by where cancer sufferers live and what resources are available locally. Certainly, breast cancer screening rates are lower for certain populations in rural or remote areas: between 1992 and 2005, for example, the BreastScreen participation rate for Aboriginal and Torres Strait Islander (ATSI) women, was 32%, compared with a national rate of 56%.²¹ Five-year crude survival rates for Indigenous women in regional Australia are also significantly lower compared with non-Indigenous women (65% versus

82% respectively for the period 2002-06; Figure 6).

In addition, while average screening rates for women in regional and remote locations are as high as for city dwellers, women from these communities tend to have mastectomies at a higher rate than women who live in the cities.

According to Dr Zorbas, rural women’s decisions about treatment options may be based on factors such as availability of services and length of time away from home. “This may be because breast conserving treatment almost always requires radiotherapy, and only specific centres across Australia can deliver this”, she says. For those needing to access radiotherapy, sometimes hundreds of kilometres away, the average length of time away from home is about six weeks. It’s a long time for these women to be away from home, especially as at least a quarter of them are likely to be under 50, many with young or teenage children at home. Many find it too difficult to manage and opt for a mastectomy.”

Professor Bishop says there are big cultural barriers to contend with: “In poorer groups the health literacy is very low, so they don’t pick up the health messages as easily. It’s not that they don’t hear the message, they do not hear it in a form they can understand or trust.”

Reaching rural communities

According to Professor Olver, there are well-recognised disparities in participation in breast screening trials between women from culturally and linguistically diverse (CALD) and ATSI groups, and women from mainstream groups. These are being addressed, but action is limited by the resources available. He says all research has to go through Aboriginal ethics committees, and some question the benefit unless the research is guaranteed a positive outcome. It is important for funding bodies and individual researchers to further develop and implement strategies that increase the involvement of ATSI and CALD groups in breast cancer research projects, especially those that involve clinical and population-level interventions.

The magnitude of the problem is well known. Community meetings have been held throughout the Aboriginal communities that stretch across Outback Australia. Training programmes have been developed and implemented in many communities. The federal government has also spent A\$560m

²⁰ Smoking, obesity and treatment rates from Professor Olver, unpublished research.

²¹ BreastScreen Australia Program, *Evaluation Final Report*, op cit.



Case study 6: Canada's nurse navigators

Canada shares with Australia several characteristics, including population size, wealth and the healthcare challenges posed by geographical vastness. Northern Health, one of six regional health authorities in British Columbia, covers an area nearly the size of France with a population of only about 350,000 people. The challenge it faced was to simplify the steps in the breast cancer field to eradicate unnecessary delays. With limited resources, it is using an innovative mix of stakeholder engagement, technology and multidisciplinary care.

Within the region covered by Northern Health, the biggest urban centre is Prince George with 76,000 residents, but it is at least an eight-hour drive from any major city. In such a rural environment, says LaDonna Fehr, regional oncology leader for Northern Health, "you have to be able to offer a certain level of service yourself".

The health authority therefore offers ten systemic therapy centres across the region, each staffed by an oncology nurse and a doctor with special training in overseeing the management of oncology treatment. There is also a regional team that uses teleconferencing to give patients access to social workers and specialised pharmacists.

Even with these centres, however, travel times for patients in this sparsely populated area are frequently lengthy, and repeated visits to medical professionals are much more time consuming than in an urban setting. For breast cancer, it often used to take patients numerous, multi-hour car rides over the course of six to eight weeks to go from the first finding that something might be wrong to a treatment plan. In some cases, this period stretched as long as 12 weeks. Even where this did not affect care outcomes, the added worry and inconvenience that it causes at such a stressful time for patients and families constituted an immense burden.

Northern Health therefore looked at creating a "nurse navigator" programme to help patients get through the steps on their cancer treatment process faster. The programme, an initiative of the Northern Cancer Control Strategy (a partnership between Northern Health, the province-wide BC Cancer Agency and the Provincial Health Services Authority), focused on enhancing cancer care in the

North. For breast cancer the initial step involved getting together in one place, for the first time, everyone involved in the entire care process in order to map out the stages and consider how to simplify it. A group of 18 people, including patients, medical professionals and even administrative staff who handle bookings, met in four four-hour sessions.

Ms Fehr recalls that their map of the care stages was "a huge document that covered I don't know how many feet. Everybody found out where the gaps in care were. We found a number of unnecessary wait times that we could eliminate with one decision and no money. Someone would say, 'We wait two weeks to do that? We could get that decision by picking up the phone'."

Not all the simplifications were so easy or inexpensive, but the result was a much more streamlined process provided by the breast clinic in Prince George. Although not yet a one-stop shop, the clinic has oncology surgeons, plastic surgeons and oncology nurses. At the weekly clinic, those sent by their doctors are able to see a number of referrals and a surgeon on the same day. If a biopsy is needed, the results are available in a few days so that it is possible to return the following week for a consultation.

Moreover, helping patients to understand what is happening and explaining what comes next have become a part of everyone's role. Under the new system, the goal is to go from the first worrisome findings to a treatment plan within two weeks, and with at most two trips to the clinic. Ms Fehr says patient satisfaction surveys indicate that they feel better informed and happier with the experience as a result.

The nurse navigators have several ongoing roles in the new system. In Ms Fehr's words, they are in charge of the "continued maintenance of the journey. We have taken away the silos, but somebody has to make sure that we have people who are fully versed". Thus, as personnel change, the nurses ensure that new arrivals are quickly brought up to speed on their roles.

Next year a BC Cancer Agency regional cancer centre will open in Prince George. This will help in ongoing efforts to reduce further the time involved in the care process and to create a truly one-stop shop for cancer care in the region.

building regional cancer centres to improve access to treatment and support for cancer patients in rural and regional Australia.

Working closely with rural and Indigenous communities to better understand their needs and concerns is a top priority for Cancer Australia, BCNA and other bodies like the McGrath Foundation (see case study 7). Over the past few years, the NBOCC (now part of Cancer Australia) has worked collaboratively with communities to engage Indigenous women on breast cancer issues. Local forums



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provide the opportunity for Indigenous women, including elders, to share their experiences through story telling with local health workers and cancer experts.

However, many think significant progress is years away, principally because there are so many other competing health problems in remote and rural communities. The problem of “closing the gap” applies to virtually all health conditions, and breast cancer is no exception. Long-term problems such as overcrowding, poverty and poor health combine with people who place great emphasis on tradition and the advice of their elders, as opposed to outside experts.

BCNA admits it is not as influential in these communities as it would like to be. “The Network is representative and has good success in reaching people in rural and remote areas,” says Ms Swinburne. “But we don’t have good coverage of underserved populations ... some cultures don’t even have a word for breast cancer.”

Geographical discrepancies in outcomes are another instance of fragmentation in breast cancer control. As with many of the challenges highlighted in this report, there is no easy solution—or it would surely have been implemented by now. Nevertheless, improved co-ordination is again the best starting point. Case studies 6 and 7 show common approaches in Canada and Australia to combating the problem of connecting care across vast distances, thereby helping to ensure all women have the best chance of detecting, treating and surviving the disease.

Case study 7: The McGrath Foundation

Glenn McGrath, a former national-team cricketer, and his wife, Jane, set up The McGrath Foundation to fund specialist breast care nurses following Jane’s personal experience with the disease. The McGrath Foundation’s mission is based on the idea that every Australian family suffering from breast cancer should have the support of a specialist nurse who can act as a patient advocate and provide practical and emotional support, as well as co-ordinate care. Importantly, breast cancer sufferers can apply directly to the foundation; they do not need a health professional to open the door for them.

The idea of a breast care nurse is hardly new—there are variations of the model across the world. But the foundation has taken an innovative approach and redefined the model by setting specific qualifications for nurses and being very clear about how the role should work.

“As long as the McGrath Breast Care Nurses adhere to our model, we supply the funding,” says Kylea Tink, CEO.

Improving access across the country is an important goal for the foundation. “We know the demand is there; we get applications from [across] the community,” Ms Tink says. “We have done our analysis and

we know the gaps that need to be filled.”

Such gaps include improving access in remote communities. “We set ourselves a target to put healthcare nurses into communities to support families where they are most needed,” says Ms Tink. “By definition, that means 89% of McGrath nurses are based in rural and regional communities—those remote places in the Outback that have few resources and where access to such help is non-existent.”

Many McGrath Breast Care Nurses work with Aboriginal Health Services workers. This has led in some instances to education programmes organised specifically for Indigenous Australians.

In 2008 Jane passed away. At that time the Foundation had four nurses; it now has 68. With an estimated 15,000 new breast cancer diagnoses each year, Ms Tink calculates that McGrath nurses are supporting half the families experiencing breast cancer. “Based on the current environment we estimate we will need around 150 McGrath Breast Care Nurses across Australia to help meet the need of families newly diagnosed with breast cancer in any given year.”

Each nurse costs around A\$350,000 over a three-year period (the minimum that the foundation supports). This implies that complete coverage would require an additional spending of A\$28.7m over the same timeframe—very little considering the benefits to families that otherwise would have to face the daunting treatment process alone.



Conclusion: Identifying future priorities

Compared with other rich countries, Australia fares well when it comes to its bid to control breast cancer. Funding is plentiful, collaboration between cancer control organisations is sound, and there is a commitment to implementing evidence-based best practice across the field. But the race is not yet run.

On the research side, Ms Renouf of the NBCF says it is important to have up-to-date information on where Australia's cancer research strengths lie compared with international efforts. "We want to be able to identify barriers to progress in Australia, and what interventions might remove those barriers," she says. "We need to identify the significant gaps in funding for cancer research in Australia and implement strategies to plug those gaps."

In order to identify its own strengths, Australia also needs better co-ordination and the timely provision of more usable data. A national system of data collection with information that can be shared, and which includes outcomes and monitors clinical performance, is the first step.

The importance of having a national source of credible information was highlighted in the recently released *Cancer Australia Strategic Plan 2011-2014*, which identifies key issues and strategies to improve cancer control. In this report, Dr Zorbas says Cancer Australia aims to provide trusted and up-to-date information to guide clinical best practice and inform consumer decision making. "Central to our efforts is the use of evidence to advance improvements across the cancer continuum and the use of innovative approaches to deliver best-practice care and support."

In terms of early detection and secondary prevention, Australia must address disparities in treatment through regional cancer centres. Professor Boyages emphasises that Australia needs comprehensive breast cancer programmes and wider screening to capture women younger than 50 and over 70. Even for the target age group, BreastScreen Australia's participation goal of 70% has not been met. Worse, re-screening rates are low, with under two-thirds of women coming back two years later.²²

²² BreastScreen Australia Program, *Evaluation Final Report*, op cit.



Getting it all together

Connecting Australian breast cancer care

Then there are the broader challenges to improving treatment. Many experts cite concerns about having a sufficiently large and high-quality oncology workforce to handle the growing number of diagnoses. Australia must also ensure that what is discovered from research is translated into improved treatment. At the other end of the continuum, more needs to be done for sufferers and survivors: Ms Swinburne of the BCNA says identifying breast cancer patients at risk of psychosocial after-effects, and establishing means for their support, are also a vital priority.

Finally, Australia must guard against complacency. According to some interviewees for this report, owing to recent advances, there is a sense at some levels that breast cancer had been “done” and can be ticked off the national agenda. They warn that it is crucial that the country does not become complacent because of the progress already made. If Australia “takes its foot off the pedal”, as the head of one NGO puts it, it risks losing the momentum already gained.

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