The Economist INTELLIGENCE UNIT

BREAST CANCER PATIENTS AND SURVIVORS IN THE ASIA-PACIFIC WORKFORCE

Australia: Forging a path in Asia

Sponsored by:

Pfizer Oncology

About the report

Breast cancer patients and survivors in the Asia-Pacific workforce. Australia: Forging a path in Asia is an Economist Intelligence Unit report, sponsored by Pfizer Australia Pty Ltd, Sydney Australia. This report draws upon interviews and research conducted in August-September 2018 on the topic of return-to-work for breast cancer survivors in Australia. Marianne Bray was the author and Michael Gold was the editor. We would like to thank the following experts for contributing their time and insight:

- Dorothy Frost, group manager, research and innovation, IPAR, Melbourne, Australia
- Camilla Gunn, founder, Cancer Workplace Solutions, Sydney, Australia
- Georgia Halkett, associate professor, senior research fellow, School of Nursing, Midwifery and Paramedicine, Curtin University, Perth, Australia
- Annie Miller, director, cancer support services division, Cancer Council, Sydney, Australia
- Kerry Patford, breast care nurse, clinical nurse manager, McGrath Foundation, Benalla, Victoria, Australia
- Dianne Sheppard, senior research fellow, Monash University Accident Research Centre, Melbourne, Australia

It also draws upon an advisory board of global authorities who provided context and background on this topic. We would like to thank the following individuals for contributing their time and insight:

- Ziv Amir, honorary professor, cancer rehabilitation, University of Salford, UK
- Bogda Koczwara, medical oncologist and senior staff specialist, Flinders Centre for Innovation in Cancer, Flinders University, Adelaide, Australia
- Anja Mehnert, head, psychosocial oncology, department of medical psychology and medical sociology, University of Leipzig Medical Center, Germany
- Rebecca V Nellis, executive director, Cancer and Careers, New York, US

Australia: key data

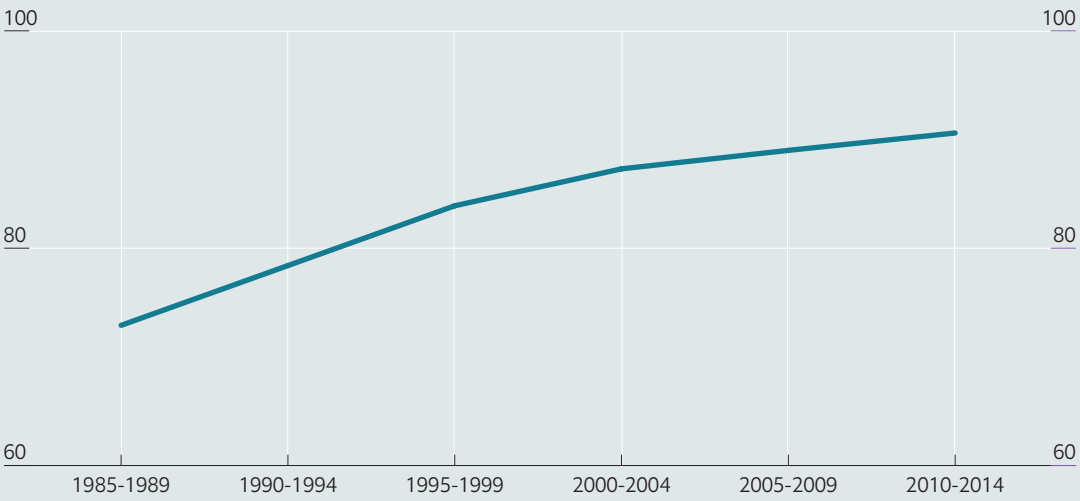
- Crude breast cancer incidence rate per 100,000 (2018): 149.3[1]
- Breast cancer prevalence (five year) per 100,000 (2018): 634.5[2]
- Labour force participation rate, general (2017): 77.4%[3]
- Labour force participation rate, women aged 40-64 (2017): 72.3%[4]
- Unemployment rate, general (2017): 5.8%[5]
- Unemployment rate, women aged 40-64 (2017): 3.0%[6]

The extent of the challenge: high burden of disease and steep losses

Australia has one of the highest rates of breast cancer in the world, coming in at 15th place, higher than New Zealand or the US, but lower than many European counterparts.[7] The number of women diagnosed with breast cancer is rising, with new cases more than tripling between 1982 and 2014.[8,9] One in eight Australian women will be diagnosed with breast cancer by the time she turns 85,[10] although fewer women are dying from the disease, with Australia boasting one of the lowest mortality-to-incidence ratios in the world (see chart on next page).[11] Between 1985-1989 and 2010-2014 the five-year relative survival rate rose from 73% to 91%.[12]

Chart I. What doesn't kill you ...

Australia breast cancer five-year survival rate, 1985-2014 (%)



Source: Cancer Australia

[1] Cancer Today database, IARC, accessed September 24th 2018

[2] Ibid

[3] OECD Datastat, LFS by sex and age - indicators, accessed September 24th 2018

[4] Economist Intelligence Unit calculations based on data from OECD Datastat, LFS by sex and age, accessed September 24th 2018

[5] OECD Datastat, LFS by sex and age - indicators

[6] Economist Intelligence Unit calculations based on data from OECD Datastat, LFS by sex and age

[7] Cancer Today database, IARC, accessed October 6th 2018

[8] *Breast cancer in Australia: an overview*, Australian Institute of Health and Welfare, October 2012

[9] Breast cancer in Australia database, Cancer Australia, accessed October 16th 2018

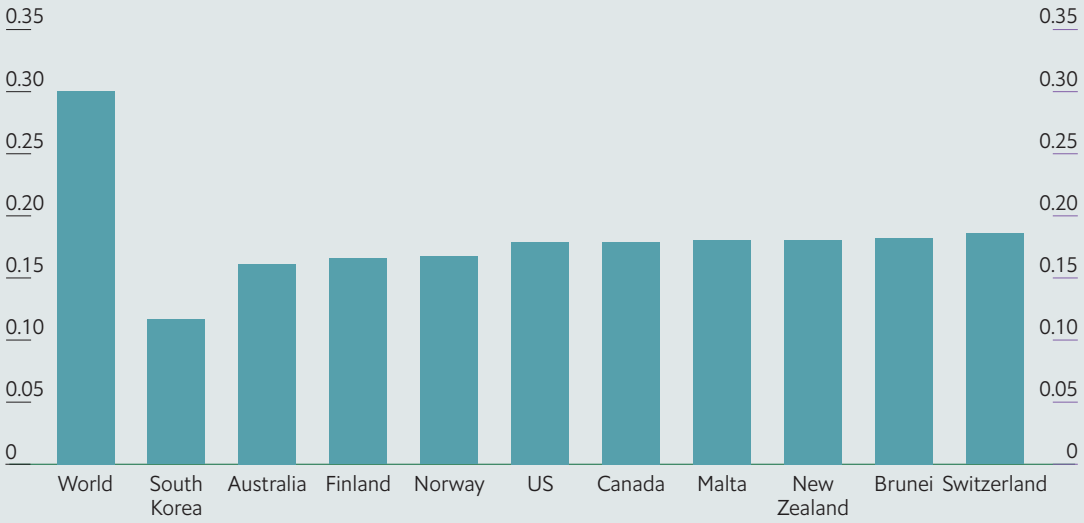
[10] Current Statistics in Australian Breast Cancer, Breast Cancer Network Australia

[11] Male breast cancer occurs but only rarely, with an age-adjusted incidence below one per 100,000 across Asia-Pacific (Diana Ly et al, "An International Comparison of Male and Female Breast Cancer Incidence Rates", *International Journal of Cancer*, 2012). This study therefore deals exclusively with female breast cancer

[12] Breast cancer in Australia database, Cancer Australia

Chart II. Healthy down under

Breast cancer mortality-to-incidence ratio, global and top ten countries



Source: EIU calculations based on data from IARC/WHO Cancer Today

At the same time, more women, especially those aged 55 or older—the age when breast cancer risk starts to grow markedly—are working.[13] Research shows a diagnosis can have a big impact on hours worked and financial costs. A 2016 report showed that median household hours worked per week dropped by 50% during treatment compared with 12 months prior to diagnosis, and remained 13% lower 12 months after treatment.[14] The report estimated that median total financial loss—out-of-pocket and indirect financial costs, such as loss of income—during the first two years post-diagnosis was A$9,389 (US$6,690).[15]

For cancer as a whole, another report showed almost half (46%) of people with cancer were not employed, resulting in a reduction of A$1.7bn to Australian GDP.[16] Healthy people were three times more likely to be employed full-time than those with cancer.

[13] Gender Indicators, Australian Bureau of Statistics, January 2012

[14] *Financial impacts of breast cancer in Australia*, Deloitte, November 2016

[15] Ibid

[16] Nicole Bates et al, "Labour force participation and the cost of lost productivity due to cancer in Australia", April 6th 2018

The global context: no easy generalisations

Return-to-work is a difficult issue around the world. Rebecca V Nellis of Cancer and Careers, a US non-government organisation (NGO), says the issue "has been so under-discussed that you need to reach across all borders to see the full picture". Few diagnosed with breast cancer wish to leave the workforce permanently, as work is both an economic necessity and often psychologically beneficial. An examination of what research does exist internationally is therefore helpful for setting the context of this challenge in Australia.[17, 18] It can be looked at via the following domains:

- **Medical outcomes and treatment.** Ongoing levels of pain, fatigue and depression, all frequent conditions among survivors, understandably impede resumption of employment. Treatment specifics are also important. Certain interventions, for example chemotherapy and radiotherapy, correlate with lower return-to-work rates. Clinicians should thus consider employment goals when discussing therapy choices. Traditionally they have been reluctant to do so, although experts indicate this may be changing.

- **Workplace relations.** Various studies support the central role that employers and co-workers play. Many employers are supportive but lack knowledge of what to do, probably because company policies need to be tailored to the individual organisation and, even then, require extensive flexibility. Both Anja Mehnert of the University of Leipzig Medical Center in Germany and Bogda Koczwara of Australia's Flinders Centre for Innovation in Cancer explain that what works in a given case depends on specific employee and employer circumstances. Big companies may be able to offer counsellors, employee assistance programmes, and retraining and upskilling opportunities, while small employers may lack these resources. Dr Mehnert explains that "it's very important that employee and employer have an open discussion" as early as possible after diagnosis.

- **Regulatory frameworks.** Laws can profoundly impact the success of return-to-work rates, but it is difficult to generalise beyond that. The rules governing return-to-work vary widely by jurisdiction and may involve the following:
  - constitutional rights;
  - human-rights law;
  - disability legislation and benefits; and
  - long-term sick leave rules and payments.

Lawmakers must remain aware that even well-meaning rules can create problems.[19] Granting disability pensions to cancer survivors, for example, may be appropriate, but if they are structured

[17] This section draws heavily from *The Road to A Better Normal: Breast cancer patients and survivors in the EU workforce*, The Economist Intelligence Unit, 2017

[18] The following paragraphs summarise and integrate findings from: Joanne Park and Mamdouh Shubair, "Returning to Work After Breast Cancer: A Critical Review", *International Journal of Disability Management*, 2013; Tania Islam et al, "Factors associated with return to work of breast cancer survivors: a systematic review", BMC Public Health, 2014; Régine Mbengi et al, "Barriers and opportunities for return-to-work of cancer survivors: time for action—rapid review and expert consultation", *Systematic Reviews*, 2016; and Institut National du Cancer, *La vie deux ans après un diagnostic de cancer - de l'annonce à l'après cancer, collection études et enquêtes*, 2014

[19] See also Corine Tiedtke et al, "Supporting Return-to-Work in the Face of Legislation: Stakeholders' Experiences with Return-to-Work after Breast Cancer in Belgium", *Journal of Occupational Rehabilitation*, 2012

to forbid any earned income by recipients then they may impede the kind of phased return-to-work that is often more successful than the immediate resumption of full-time duties.

- **Socio-economic considerations.** The nature of work and socio-economic status of the survivor are highly significant. In general, blue-collar, low-paid, manual workers are less likely to successfully continue with or resume employment. Low-paying jobs provide less incentive to overcome the difficulties of returning, while survivors' physical challenges make manual labour much harder.

Adding to the difficulties, all relevant issues overlap in a complex mesh. Progress, therefore, is likely to come from multi-faceted efforts. At the small scale, research into highly targeted interventions has shown little effect, but some evidence exists to support programmes that address patients' physical, psycho-social and vocational issues simultaneously.[20] Ziv Amir of the University of Salford in the UK cites "lack of communication between multiple stakeholders, including employees, employers, clinicians, regulators and trade union officials", as the single biggest obstacle, while Dr Koczwara says the key to progress is getting all stakeholders to support two principles: "work is valuable and everybody is different", so help needs to be flexible to succeed.

[20] Angela de Boer et al, "Interventions to enhance return-to-work for cancer patients", *Cochrane Database of Systematic Reviews*, 2015

Australia: a country at Asia's cutting edge

"One of the key things is to inform every organisation of what the rights are, and how they should be working flexibly with people."

- Annie Miller, Cancer Council

Australian studies show cancer survivors there share the same barriers and opportunities in work as their overseas peers,[21] but the country has some significant strengths in this area. The nation has a strong reputation in cancer control generally. It boasts an advanced medical system with universal health coverage and provides high standards of treatment and survivor care.[22] When it comes to breast cancer specifically, women aged 50-74 are entitled to a free mammogram every two years,[23] and a number of groups, from the government, NGOs, academia and the private sector, are present at the national, state and local level. An Economist Intelligence Unit study from 2016 ranked the country first among ten Asian-Pacific economies on management of the disease.[24]

Australians are also generally well informed about the disease. Many patients no longer see breast cancer as a death sentence, but more as a disease to be managed, and a return to paid work as a significant milestone on the road to recovery. Much of this lies in Australia's strong advocacy groups, including Breast Cancer Network Australia (BCNA) and Cancer Council Australia. These groups organise nationwide activities, are skilled at lobbying, and have the resources and staff to deliver significant results, according to Dr Koczwara. Just this year the BCNA, for example, published a State of the Nation report to drive action on breast cancer.[25]

NGOs also engage with consumers and the community, boosting awareness of and support for breast cancer patients. Groups like the McGrath Foundation provide care in both urban and rural areas. Their 120 nurses, some of whom are funded by the government, have helped more than 67,000 families across Australia since 2005. They guide patients from diagnosis throughout treatment and beyond, with work being a component.[26] "If someone needs to work then we need to know that, so we can work with the employee about how to get them back to work safely," says Kerry Patford of the Foundation, adding that many of her working-age patients need the income and work on farms.

For their part, employers are compelled by law to make "reasonable adjustments" for patients to keep working, as cancer is considered a disability. Employees in treatment or recovery have the right to ask for flexible working arrangements, including working from home, changing start and finish times, and varying hours, including working part-time or job-sharing.[27] While the regulatory framework is strong, there is some confusion about what adjustments should look like and patients (as well as healthcare providers and employers) may not be aware of entitlements under the law. "One of the key things is to really inform every organisation of what the rights are, and how they should be working flexibly with people," says Annie Miller of Cancer Council.

In a bid to inform patients, their care providers and employers, the Flinders Centre for Innovation in Cancer has an online website dedicated to working after a cancer diagnosis; the Cancer

[21] Georgina McKay et al, "Return to Work and Cancer: The Australian Experience", *Journal of Occupational Rehabilitation*, September 2012

[22] *Breast cancer in Asia*, The Economist Intelligence Unit, March 15th 2016

[23] "About breast screening", BreastScreen Australia, last updated March 5th 2015

[24] The Economist Intelligence Unit, 2016

[25] *State of the Nation Report*, Breast Cancer Network Australia, June 2018

[26] About the McGrath Foundation, McGrath Foundation website

[27] *Cancer, Work & You*, Cancer Council Australia, February 14th 2017

Councils (both national and state) also host resources online.[28, 29, 30] They focus on education for all stakeholders, offering action-oriented toolkits tailored to patients, healthcare providers and employers.

"People need to have a quick checklist of questions to ask, doctors need to know how to assess people for ability to work and employers need to know what is legal and what is not," says Dr Koczwara. Alongside flexible working, reasonable adjustments can include special chairs or desks, access to a quiet room and changing roles, says Camilla Gunn of Cancer Workplace Solutions, a social enterprise that helps companies support their staff through a diagnosis.[31]

[28] Work after Cancer, Cancer Australia and Flinders University

[29] Work and cancer, Cancer Council NSW

[30] Cancer and work, Cancer Council Australia, last updated October 18th 2017

[31] Working with cancer—Australia's first toolkit for organisations, Cancer Council NSW, April 29th 2016

Still some gaps to fill: lack of flexibility and little focus on rehab

"We do not have a good welfare system for gradual return to employment."

- Bogda Koczwara, Flinders Centre for Innovation in Cancer

Despite Australia being a leader in the Asia-Pacific region, there is room for improvement if this nation of nearly 25m people is to match its counterparts in Europe around return-to-work after a breast cancer diagnosis.

One of the biggest challenges is a lack of flexibility in the welfare system, says Dr Koczwara. "We do not have good welfare support for gradual return to employment. The system tends to adopt a blunt on-and-off approach: you're either [working] or you're not. There isn't an easy way of shifting between one and the other." Sickness allowances are provided by the government for people who cannot work because of illness, although recipients are expected not to work and will lose the benefit if they return to work in any capacity (however reduced), according to Dr Koczwara.[32]

There is also little focus on vocational rehabilitation, unlike in nations like the Netherlands where it is considered part of standard medical care, says Dr Koczwara. To help address such gaps, the Australian government has funded a study to track the experiences of 70,000 survivors to analyse the physical, mental, social and economic impacts of cancer, and how outcomes vary between socioeconomic groups and different cancer types.[33]

A group of researchers, in conjunction with IPAR, a workplace rehabilitation service provider, is also pilot-testing a tailored return to "good work" scheme for breast cancer survivors.[34] According to Georgia Halkett of Curtin University and Dianne Sheppard of Monash University, who are running the project, there are best-practice guidelines for return-to-work following injury or chronic disease, but not yet following cancer. Funded by the National Breast Cancer Foundation (NBCF), their return-to-work research is testing a three-pronged approach that assesses breast cancer patients, gives them health coaching and educates workplace representatives. A trained occupational rehabilitation consultant will liaise with the patient, employer, doctor and other providers and monitor progress.

The research aims to create a toolkit that can be tailored to each individual, and if successful will be used for a national rollout. A key part of the project will involve measuring how this approach affects primary return-to-work outcomes along with more tangential outcomes, such as quality of life, values around health, work and employer, physical symptoms, psychological distress, and empowerment.

While evidence shows work is good for health, the researchers say the move back to work needs to fit with an individual's needs and circumstances. Society generally does not "hold the view that working is of benefit, until [patients] are cancer-free or in remission," says Dorothy Frost of IPAR.

[32] Payments for people living with an illness, injury or disability, Australian Government Department of Human Services, last updated August 10th 2018

[33] "Cancer Council hails landmark study in patient-centred care", Cancer Council Australia, December 6th 2017

[34] Improving support for those returning to work following breast cancer, National Breast Cancer Foundation

Oncologists are focused on the disease itself and returning to work tends not to be discussed, Ms Frost says, with employers likely "to be reticent and worried about how things might go". Already there is a view that patients need a holistic care regime that considers mental as well as physical health issues; indeed, when Ms Gunn was preparing a working with cancer toolkit, insurance companies told her anecdotally that patients who are "not supported well after a cancer diagnosis can often present later with a mental health issue, like anxiety or depression."

These studies should go some way towards determining how well Australia serves the most vulnerable, something the nation needs to do better at, according to Dr Koczwara. In Western Europe, policymakers are looking at the financial circumstances of patients, and there is significant lobbying and advocacy focusing on the cost of drugs and insurance, she adds. While the rising cost of treatment has attracted attention in recent years in Australia, the impact of breast cancer on the reduced ability to work and on financial reserves has not been the focus of discussion, says Dr Koczwara. Ms Patford agrees that it should be easier for patients to access financial advice and superannuation if they need to. "Many people are left in financial turmoil due to the processes of accessing funds," she says. "Unfortunately the systems are designed as a one-size-fits-all, when we know that each cancer experience is very different, as is each workplace."

Furthermore, a recent report from BCNA noted that while progress has been made with breast cancer, gaps in treatment and care exist, and some sub-groups of the population, including women living in rural and remote areas and Aboriginal and Torres Strait Islander women, have lower survival rates than others.[35] Other vulnerable groups include those with limited health literacy, those for whom English is not the first language and the very young, Dr Koczwara notes. "A significant proportion of women work part time or in casual positions, where job security is not high and the supports available for them to maintain employment are quite limited," she says.

Meanwhile, the vast majority (over nine in ten) of Australian businesses are small, accounting for 33% of Australia's GDP and employing over 40% of the workforce.[36] They often don't have "the awareness, policies or capacity to provide that flexibility and support to really make a difference for breast cancer survivors in their transition back to work that larger organisations can provide," according to Ms Halkett and Dr Sheppard.

[35] "Cancer Council hails landmark study in patient-centred care", Cancer Council Australia, December 6th 2017

[36] *Small Business Counts: Small Business in the Australian Economy*, Australian Small Business and Family Enterprise Ombudsman, 2016

Conclusion: an exciting time for Australia

Despite some shortcomings, Australia is clearly leading the way in Asia-Pacific. While it has one of the highest breast cancer rates in the world, it also has one of the highest survival rates, and the nation is home to a diverse ecosystem of groups working to boost outcomes for patients and survivors. Its strength in advocacy, research, treatment, laws and education means that neighbours like New Zealand are keenly watching Australia's next steps.

Although Australia has gained a lot of ground in recent years, challenges remain. Work still needs to be done in some areas of treatment and care, including ensuring enough breast care nurses are active in the community; some marginalised groups are still very vulnerable. Research is taking place to address some of these gaps, including a project looking at the impact of cancer on 70,000 patients. However, while best practice in return-to-work has been mapped out for other illnesses in Australia, it has not been done for cancer, especially not breast cancer.

Yet perhaps one of Australia's most prominent strengths is its vibrant research community, which is focusing a great deal of attention on return-to-work, as Ms Halkett, Dr Sheppard and IPAR's nascent programme illustrates. "This is an exciting time for this field", according to a written statement by the researchers provided to The Economist Intelligence Unit. Working with cancer has been recognised as a gap in the continuum of cancer care, they note, and "what is even more exciting is that Australia seems to be one of the nations leading the way in this field."

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