



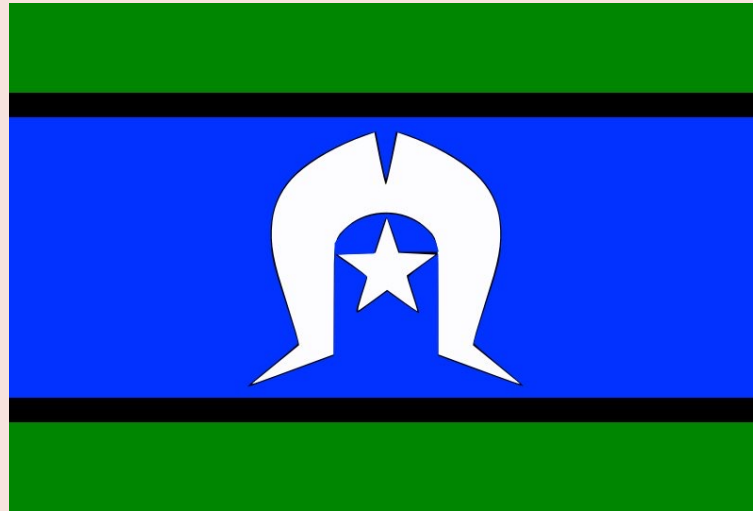
breast cancer
care wa

Innovating Survivorship Education:

Co-Design and Evaluation of a
Mindfulness-Based Breast Cancer
Recovery Program

Chandrika Gibson, Karen Lewis, Sally Dare, Linda Garrett,
Georgia Halkett

Acknowledgement of country



Breast cancer in Australia

- In Australia, **1 in 7 women** and **1 in 557 men** are at risk of being diagnosed with breast cancer in their lifetime.
- **5 people are diagnosed with breast cancer every day in WA.**
- Breast cancer is the **most commonly diagnosed cancer in women in Australia**, and the second most common cause of cancer death.

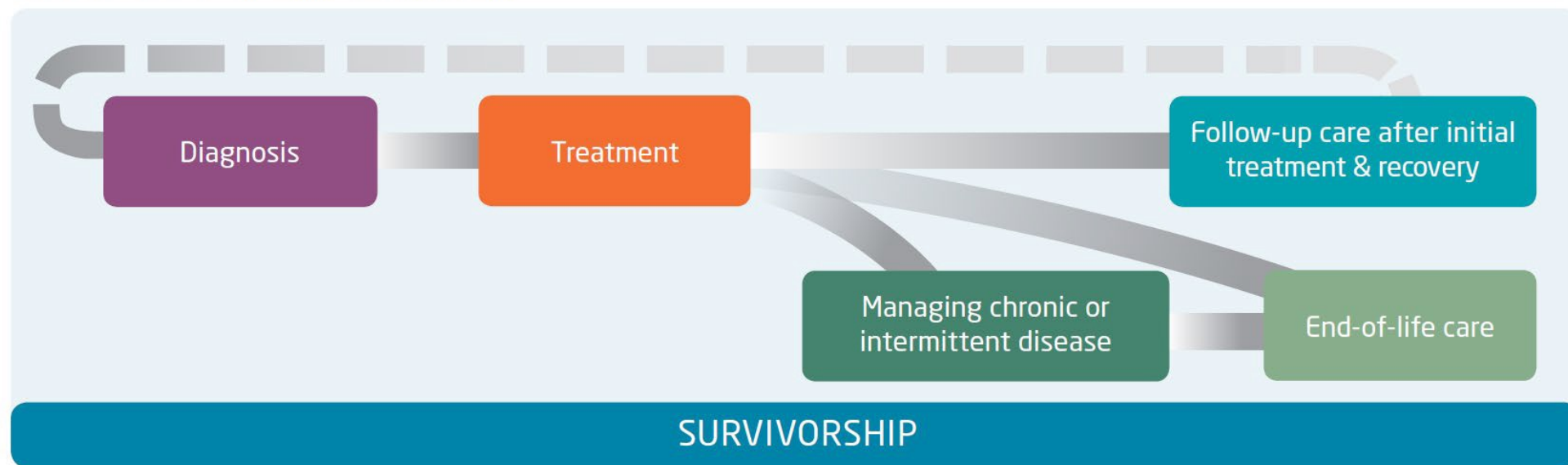


What is survivorship?

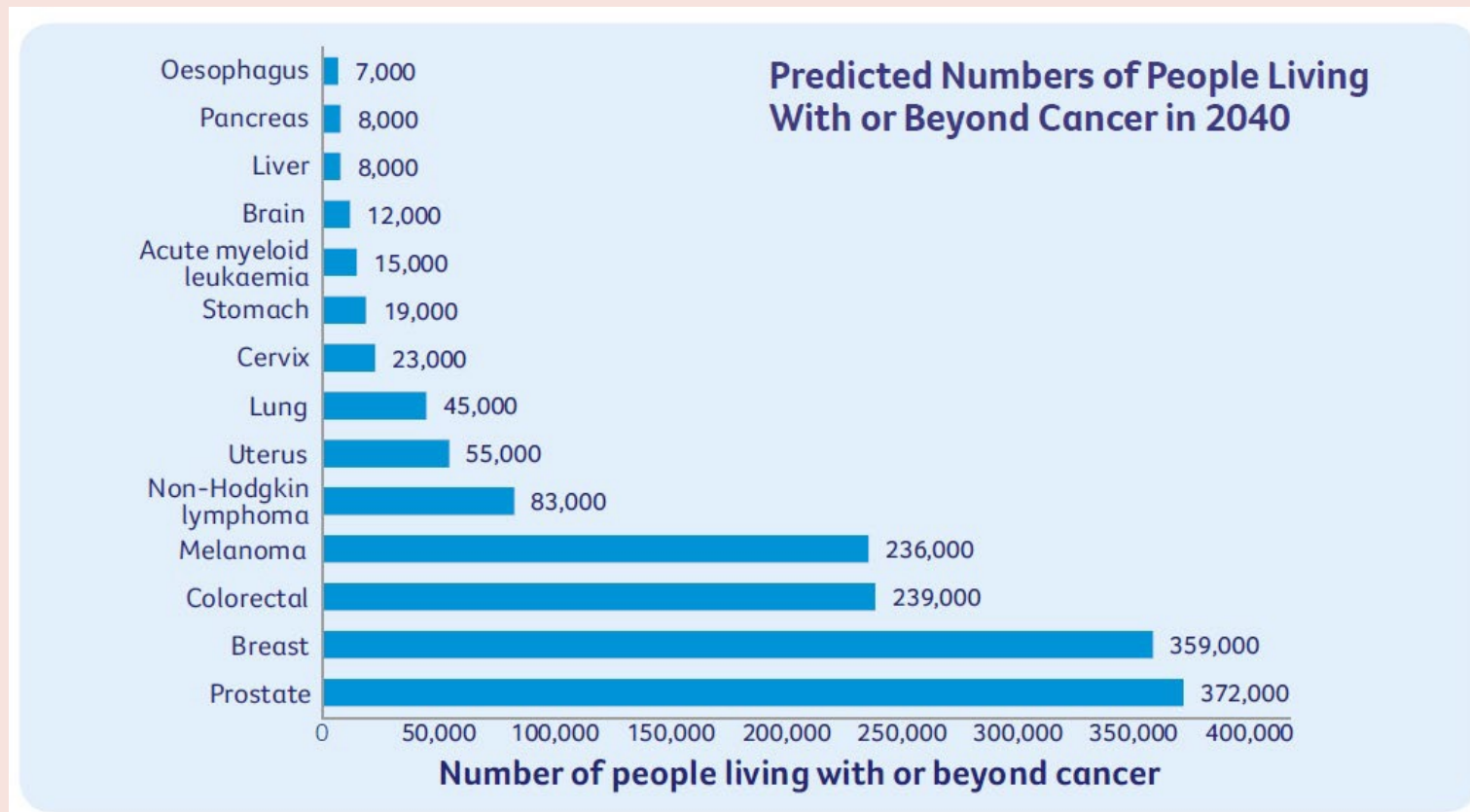
- “An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience”.

<http://cancercontrol.cancer.gov/ocs/statistics/definitions.html> Adapted from the National Coalition for Cancer Survivorship

FIGURE 1 CANCER CARE CONTINUUM *



Predicted Breast Cancer Survivors 2040



Reference: Cancer Council Victoria 2018

Why Survivorship Programs?

More people are surviving breast cancer than ever before

In WA, breast cancer is the most diagnosed cancer in women, with 1899 cases diagnosed in 2019.

The 5-year survival rate has increased from 84.7% (1995-1999) to 92.5% (2015-2019)

Why Community-based Survivorship Programs?

Post-treatment phase brings unique emotional, psychological, and physical needs

Medical oncology staff report multiple barriers to providing survivorship care (Lisy et al, 2020)

Need for evidence-informed programs tailored to the survivorship experience, delivered close to home for accessibility

Why mindfulness?

Research using mindfulness-based programs for people diagnosed with various forms of cancer have proven that an 8-week program can result in:

- enhanced quality of life
- decreased stress symptoms
- altered cortisol and immune patterns consistent with less stress and less mood disturbance
- decreased blood pressure. *Carlson et al. 2013*

After piloting this program, participant feedback has led us to this 6-week format.



breast cancer
care wa

Mindfulness-based Breast Cancer Recovery

Development and implementation of an original, online, survivorship education and mindfulness training program for survivors of early breast cancer who have completed active treatment.



breast cancer
care wa

Program Development 2022 - 2026



Needs Assessment & Literature Review



Co-design



Implementation



Evaluation



Dissemination & Continuous improvement

Ethics and Funding



Curtin University Human Research Ethics Committee (HREC) approved this study (HREC number HRE2022-0002).



Funding secured from Lotterywest COVID-19 Recovery Initiative



Support for organisations transitioning to online and hybrid service delivery

Needs assessment & Co-design

Online focus groups with $n = 18$ clients who had completed active treatment for early breast cancer

Surveys sent to 1200 clients $n = 215$ responses

Surveys and discussion with $n = 14$ BCCWA health professionals, including 7 specialist breast care nurses

Content creation in collaboration with specialist breast care nurse Karen Lewis, and professional counsellor Linda Garrett

Co-design in practice

Programs were developed collaboratively using focus groups and surveys to identify needs and preferences.

2022 Focus Groups post treatment EBC $n=18$

BCCWA specialist breast care nurses and counsellors $n=14$

Voices of:

- People with lived experience
- BCCWA specialist breast care nurses and counsellors
- Integrated with 40 years of mindfulness research



Co-design shaped

- Program priorities and content
- Language and framing
- Delivery format and timing
- Group guidelines
- Accessibility and relevance



breast cancer
care wa

Results of focus groups

Participants expressed varied interpretations of the term "survivorship," with some rejecting it due to its implications of finality.

Key themes identified included a lack of adequate support post-treatment, the emotional impact of feeling "cast off" by the healthcare system, and significant physical and cognitive changes affecting daily life.

Participants highlighted the need for personalised support programs that address psychological, physical, and social dimensions of recovery.

There was strong interest in a co-designed survivorship program that includes psychoeducation, stress management techniques, tailored exercise, and nutrition guidance.

Many participants also emphasized the importance of peer support and social connections in navigating their post-treatment journey.

Program overview

Wk 1

Mindfulness & survivorship

- Mindfulness defined
- Survivorship defined
- Creating a Survivorship Care Plan.

Wk 2

Mindfulness self-awareness

- Mindful self-inquiry
- Values & SMART goals.

Wk 3

Mindful living after breast cancer

- Applying mindfulness to late and lasting effects
- Setting SMART goals.

Wk 4

Mindful movement

- Exercise, yoga and more
- Setting SMART goals.

Wk 5

Emotional recovery

- Trauma and embodied recovery
- Mindful self-compassion and healing
- Setting SMART goals.

Wk 6

Returning to roles

- Work, hobbies, valued activities
- Setting SMART goals
- Review mindfulness skills

Program Purpose

- To enhance wellbeing by providing evidence-based educational information and resources including practical, mindfulness-based strategies for self-management after breast cancer.

Structure

- 6 x 2-hour workshops (delivered weekly)
- Delivered live online using videoconferencing technology (Microsoft Teams).



breast cancer
care wa

Program objectives

At the completion of this program, participants will:

- ✓ Be supported to articulate, understand and process the impact of cancer on life after treatment.
- ✓ Have increased understanding and insight into patterns of thinking, feeling and behaviour.
- ✓ Have developed and practiced mindfulness-based skills.
- ✓ Have experienced setting mindful SMART goals for self-management.
- ✓ Have an improved sense of self-efficacy.
- ✓ Have a guide to improved physical, emotional and psychosocial wellbeing.
- ✓ Know where to access reliable information about cancer and cancer services.
- ✓ Understand how to develop a personalised Survivorship Care Plan.
- ✓ Be more comfortable using videoconferencing technology for accessing education and support.



breast cancer
care wa

Program Impact

- 2022: Pilot 9 participants
- 2023: Physical Activity pilot
- 2024: Q2 =13; Q4 = 10
- 2025: Q1 =13; Q3 = 8
- 2026: Q2 = 10

Total MBBCR participants: 63



Evaluation: Participant Reported Experiences



"Helped me reconnect with myself after treatment"



"Gave me tools to manage anxiety about recurrence"



"I use the tools to help foster a calm approach to life after diagnosis and treatment rather than living in a world of fear and anxiety"



Evaluation: Participant Reported Experiences



"It is a really awesome program delivered by kind, caring and very knowledgeable people. I learnt a lot and will take it all with me as I try and navigate life . Thank you."



"So many great aspects, not just the mindfulness, but connecting with others, knowledge about treatment, symptoms and just the facts was really helpful in helping me to process what had happened and how to move forward."



"The goal setting was very good, I enjoyed a having a practical tool/ process to follow to set goals and move forward."

Program Evaluation

97% of participants reported that the program met "most" or "almost all" of their needs.

87% were "definitely" satisfied with the facilitation and content of activities.

Net Promoter Score: 96% indicated they would recommend the BCCWA Living Well survivorship program to others



breast cancer
care wa

Implementation Learnings

- Digital delivery does not automatically equal accessibility
- Skilled facilitation is crucial
- Clear referral pathways support reach and uptake including underserved cohorts
- Ongoing clinician partnerships build trust
- Evaluation needs to be embedded not an afterthought



breast cancer
care wa

Spotlight on nurses in survivorship program

- Skilled communication on regular follow-up and early intervention
- Evidence-based up to date information aligned with EviQ, COSA, Cancer Australia guidelines
- Survivorship Care Plans with goal setting & self-management
- Continuity of compassionate, accessible care
- Nurse-led strategies support health behaviours and endocrine therapy adherence



breast cancer
care wa

Take Home Messages

- Survivorship care remains a critical, underserved area of need
- Co-designed programs meet unmet needs
- Nurses are integral to leadership and innovation
- Nurses deliver survivorship education, support treatment adherence and empower people to live well during and after treatment for breast cancer



breast cancer
care wa

How to find out more

- Contact chandrika@breastcancer.org.au

If you or someone you know needs breast cancer support, please contact us on **(08) 9324 3703** or email **info@breastcancer.org.au**



breast cancer
care wa