

SO BRAVE

Australia's Young Women's Breast Cancer Charity

Pregnancy and Postpartum Associated Cancers Workshop



Cancer Nurses Society of Australia

Conference 2026

Rachelle Panitz and Esther White



PREGNANCY AND POSTPARTUM ASSOCIATED CANCERS PROJECT

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Australia's Young Women's Breast Cancer Charity

**Because
young women
get cancer in
pregnancy and
postpartum too.**

sobrave.org.au

Acknowledgement of Country

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Australia's Young Women's Breast Cancer Charity



So Brave respectfully acknowledges the Traditional Owners of the lands on which we operate and gather. We pay our respects to their Elders, past, present, and emerging, and recognize their enduring connection to country, culture, and community. We acknowledge the significant health gaps that exist for Aboriginal and Torres Strait Islander peoples, particularly in the area of cancer care, and recognise the need to support and improve health outcomes for Indigenous women.

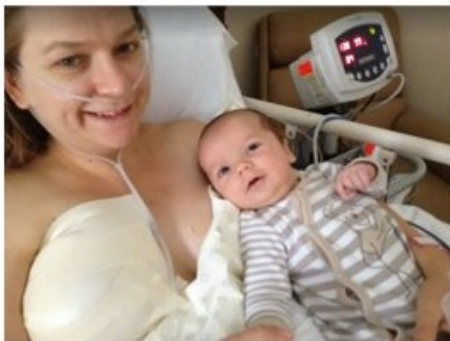
Cancer in Pregnancy and Postpartum

Rachelle Panitz
Founder and Managing Director
So Brave



I felt like the only person going through this - I never met anyone who had a similar diagnosis pathway until I started So Brave.

My diagnosis was delayed due to multiple failures in healthcare provision - from being told it was 'normal' fibrous tissue as part of my body getting ready for baby to 'normal' lactating tissue with a newborn....



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The Background

Patients left to navigate siloed care in a vulnerable stage and situation. No coordinated care and national initiative to change things for women in this space.

Lack of understanding amongst clinicians - Many clinicians may only see 1 PAC patient in their career – but for patients, the lack of coordinated care is their whole world.

Lack of data - no specific incidence data in Australia – but we're working on it. Internationally - 1:1000 – so why do we have so many?!



No woman should face cancer in pregnancy or early motherhood without specialist, coordinated care.



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PAC Project Overview

Cancer Patient Support Program Project: Pregnancy and Postpartum Associated Cancers

So Brave is delivering this two-year project as part of the Australian Cancer Plan initiative - Cancer Patient Support Program (CPSP).

A first-of-its-kind, sector-wide initiative focused on:

- improving early **diagnosis, care, and support**
- for women diagnosed with cancer during **pregnancy or up to 2 years postpartum**.
- **cross-cancers** incorporating patients from across the PAC continuum: breast, ovarian, bowel, lymphoma, leukaemia, cervical and melanoma.



No woman should face cancer in pregnancy or early motherhood without specialist, coordinated care.



PAC Project Overview

Cancer Patient Support Program Project: Pregnancy and Postpartum Associated Cancers



Project Goals

Design and deliver a first-of-its-kind **National Training Toolkit** with 2 overarching objectives:

Health Professional Education Portal

Build clinician capability, capacity and confidence in identifying and managing PAC

- CPD-eligible training modules and microlearning courses
- Webinars
- Education resources including fact sheets, check lists and guidelines

PAC Patient Portal

Co-designing meaningful, practice and culturally relevant information and resources for patients, partners and families.

- Navigation tool
- Support channels
- Self advocacy toolkit
- Information and emotional & mental health resources

The work so far

To date we have engaged approximately 300 stakeholders to inform development of the National Training Toolkit, formed partnerships with health sector peak bodies and national and international experts to strengthen diagnosis, care, and data frameworks. We are prioritising ongoing co-design and collaboration with lived-experience advocates Indigenous and culturally and linguistically diverse communities to deliver a purposeful PAC patient portal.



3 Policy Roundtables in Brisbane, Melbourne and Sydney engaging over 100 policy makers, clinicians, researchers and lived-experience advocates attended to discuss opportunities for clinical improvement, multidisciplinary coordination and complex and intersecting challenges faced by women diagnosed with PAC.



3 online Patient Engagement Sessions and digital survey to hear diverse lived-experiences, insights and priorities to help shape PAC Patient Portal tools and resources.



Formal Clinical Advisory Board established and specialist working groups with researchers, clinicians, and advocates.



Formal Patient Advisory Group established to partner in the co-design of the PAC Patient Portal.
Completed thematic analysis of patient and community insights into gaps and solutions within PAC,



“I honestly sometimes think, I don’t know how anyone navigates this system without someone holding their hand.

We have begun to plan for promotion of the project across various platforms and initiatives to continue momentum and collaboration for the creation and launch of the National Training Toolkit.



- ‘So Brave’ digital media and platforms (including the So Brave Podcast)
- Cancer Nurses Society Australia (CNSA) conference
- Partnerships with NFP Peak Bodies across cancer space

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Patient Engagement

What we heard - Key themes heard by patients and community in 2025 PAC consultations and discussions.

Delayed diagnosis and dismissal

Symptoms were often attributed to pregnancy, breastfeeding, or age, leading to misdiagnosis or delayed diagnosis and requiring women to strongly advocate for appropriate care.

Emotional impact and isolation

Women described significant emotional distress, isolation, and grief while navigating cancer during pregnancy or early motherhood, including disruption to expected motherhood experiences.

Gaps in care coordination and support

Care was often fragmented across services, with limited access to navigation, psychosocial support, and clear communication between providers, compounded by system and workforce pressures.

Limited awareness of pregnancy-associated cancers

Low awareness within parts of the health system contributed to inconsistent diagnosis and treatment pathways, with gaps in support for fertility, menopause, and mental health.

Self-advocacy burden

Many women needed to actively self-advocate and rely on personal research or informal networks due to limited structured guidance or navigation support.

Importance of peer and community support

Peer support was consistently identified as essential for emotional validation and practical guidance, though access was not always consistent or equitable.

Inequities in access and experience

Significant disparities were reported for rural and remote women and First Nations women, including barriers related to access, cultural safety, cost, and service coordination.

” **You can't comprehend it – you have cancer, you are pregnant – all at the same time. So very, very full on.”**

3 Policy Development

Roundtables held in Canberra, Brisbane and Melbourne

Speakers from across healthcare, government, lived-experience and research to address diagnosis pathways, treatment and supportive care management

Key takeaways:

delayed or dismissed diagnosis despite patient proactivity

Clinical knowledge and education gaps

Maternal health overshadowed

Data Gaps and Research Limitations in PAC

Single Point of Contact for PAC Care

Strengthening Multidisciplinary Coordination

System Navigation Support Across Care Settings
Urgent and Unmet Emotional, Psychological, and Peer Support Needs
Improving Holistic Support for Breastfeeding, Bonding, and Early Motherhood
Strengthening Access to Practical, Financial, and Social Support



“You can’t comprehend it – you have cancer, you are pregnant – all at the same time. So very, very full on.

Hospitals need to be a bit more human.”

Isla (VIC)



Who's involved? Enhanced Multi Disciplinary Teams

Medical Oncologist
Surgeon / Anaesthetist
Specialist Cancer Nurse

Obstetrician / Gynaecologist
Paediatrician / Neonatologist
Lactation Consultant
Midwives

Pharmacist Home - 1300 MEDICINE

GP

Peer Support

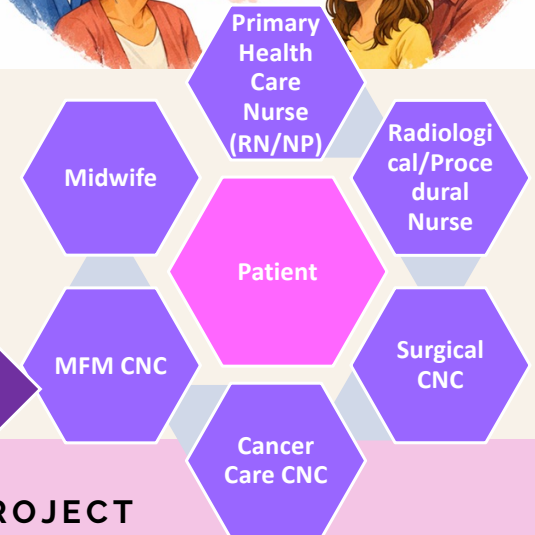
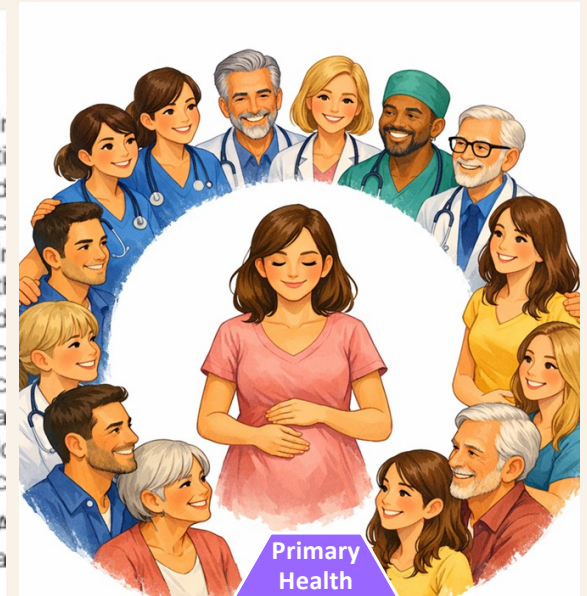
Mental Health Support

??Clinical Trials Team

FIG 1. A multidisciplinary framework for management of cancer during pregnancy.



FIG 2. Multidisciplinary care team members to consider optimizing care of the pregnant patient with cancer.



Primary Health Care

Obstetric
Physician /MGP

Screening
Physician

Surgical
Specialist

Cancer
Specialist

Maternal Fetal
Medicine

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Overcoming “Specialist Silos”

Communication, Collaboration, Consistency & Compassion!

*The role of the specialist cancer nurse
in the care of a pregnant cancer patient*

- Key member of multidisciplinary team and “subject matter expert”
- Consistent point of patient contact and information delivery
- Holistic Assessment – patient goals; clinical, educational & supportive care needs
- Collaboration and communication across specialist services
- Referral to Internal & External stakeholders e.g. Allied Health; community support services
- Therapeutic transitions and Healthy Handovers



International Best Practice

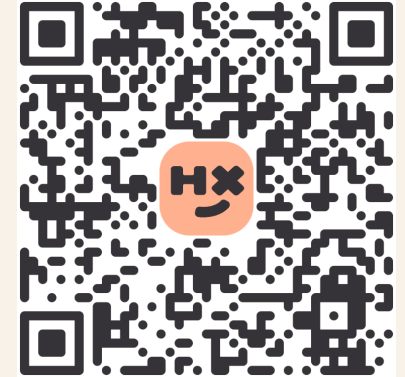
- ASCO, ESMO and FIGO Guidelines – Cancer in Pregnancy
- New ESGO Cancer in Pregnancy Textbook being produced
- ABCIP/INCIP – advice and research

And....

- **1st International Pregnancy and Postpartum Associated Cancers Online Symposia – 16 July 5pm-9pm AEST:**

including international speakers from Australia, UK, US, Netherlands across:

- Radiotherapy
- Chemotherapy
- Breastfeeding/Lactation
- Supportive Care



Acknowledgements

We are so thankful for the incredible women who have invited us to journey with them and share in their stories: it is truly an honour and privilege.

We acknowledge the women for whom there will be no cure and remember those who have said a final farewell. You have each left an indelible imprint on the hearts and lives of those around you.

We give thanks for the little people who are living testimonies of what it means to fight for life with courage, determination and most of all, love.



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Thank You

Connect with us

E-mail

team@sobrave.org.au

Website

sobrave.org.au

*References and
Resource List
available on our
new website!!*

Let's Make A Change Together.

Thank you for your time and for being part of this conversation.
Together, we can continue to drive meaningful change.

To get involved or learn more about So Brave's PAC project,
please scan the QR code & connect with us.



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