Advancing Supportive Care for Ocular Melanoma Patients: A Collaborative Nursing Model in Australia

Peta Holly
Specialist Melanoma Telehealth Nurse
Melanoma Patients Australia (MPA)

Authors

- Peta Holly (1),
- Aleya Stevenson (2)

Affiliations

- Melanoma Patients Australia (1)
- Queensland Ocular Oncology Service supported by Melanoma Institute of Australia (MIA) (2)

melanoma.
patients
australia

Acknowledgements

Acknowledgement of Country

I acknowledge Traditional Custodians of the land on which I am presenting today, the Whadjuk Nyoongar people and pay my respects to Elders past and present.

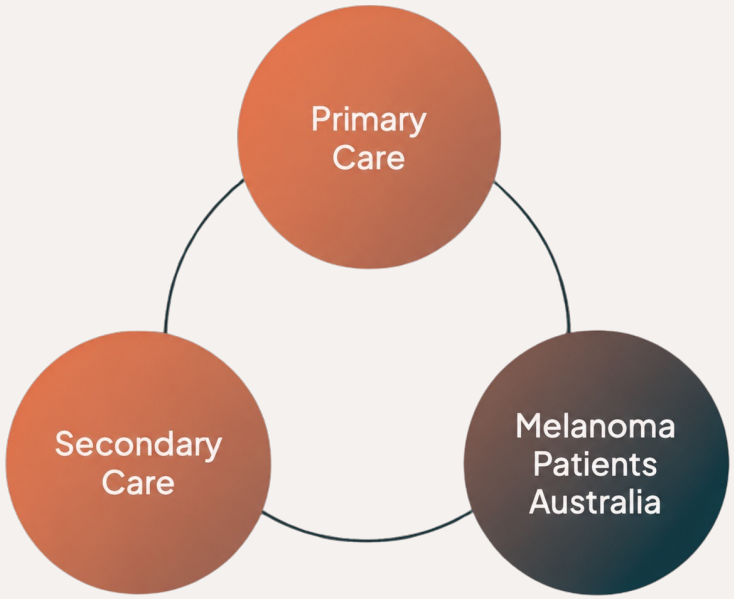
Acknowledgement of Lived Experience

I gratefully acknowledge all people affected by melanoma who have shared their lived experiences to inform and guide our work. Their courage, insights and willingness to contribute to our work, provides invaluable perspectives to help drive meaningful change and improve the support we provide.

melanoma.
patients
australia

Melanoma patient support through connected care

- **We deliver high-quality, patient-centred, specialist melanoma telehealth nursing** and community support programs.
- **We are a recognised Implementation Partner for Australia's Cancer Plan**.
- We are funded by the Department of Health, Disability & Ageing as a melanoma specialist support service provider as part of **Australian Cancer Nurse & Navigation Program (1)**



melanoma.
patients
australia

Our Vision

A nation where no one affected by melanoma walks alone.

Our Purpose

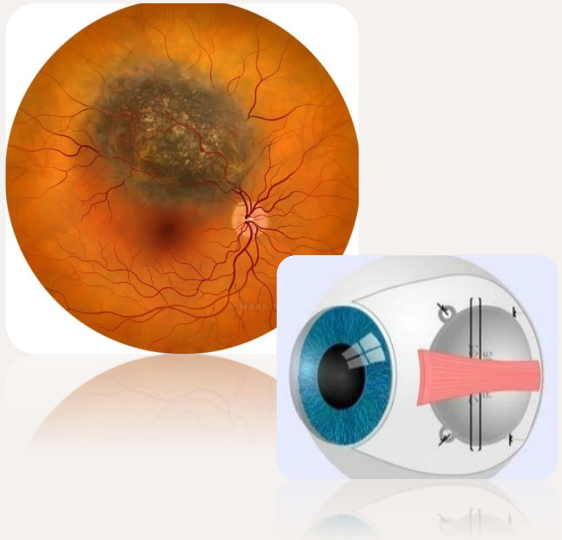
To support, connect and advocate for Australians affected by melanoma.

melanoma.
patients
australia

CNSA 2026 Congress

Elevate Cancer Themes

Innovate, Integrate, Educate, Advocate



CASE STUDY REFLECTION:

Aim: To evaluate how coordinated care between an ocular melanoma clinical nurse and a specialist melanoma telehealth nurse can improve supportive-care delivery and enhance the patient experience, for a patient in early survivorship post plaque brachytherapy (radiation) treatment for primary ocular melanoma.

melanoma.
patients
australia

Background / Introduction: What is Ocular Melanoma

THE BASICS

Rare – 5 in 1 million

Risk of developing ocular melanoma as a primary cancer Cancer of the pigment-producing cells (melanocytes) inside the eye

- Most common primary eye tumour in adults; (5-7% of all melanomas)
- Most develop in the uvea (choroid, ciliary body, iris) — uveal melanoma used ‘interchangeably’
- Often detected incidentally during routine eye exams — frequently asymptomatic in early stages
- ~200 Australians diagnosed each year, average age of diagnosis 61; more common males (2)

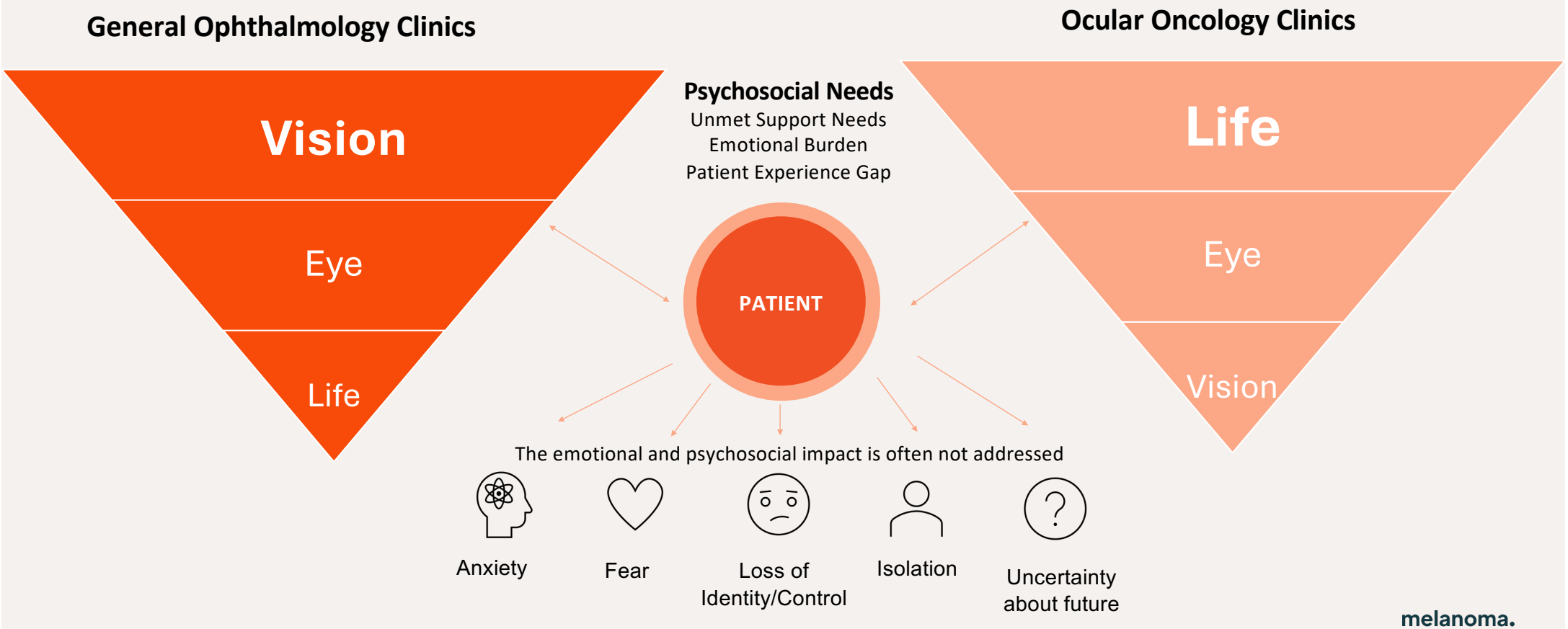
NOT SKIN MELANOMA

Although they share a name, ocular melanoma and skin melanoma are different and distinct diseases

- UV radiation is not a clearly established risk factor (unlike skin melanoma)
- Treatment: plaque brachytherapy (radiation) most common enucleation (eye removal) may be required— not the same as skin melanoma treatment
- Up to 50% may develop metastatic disease, most commonly to the liver
- Requires lifelong surveillance of the eye and for metastatic spread across different institutions
- Primary care managed in ophthalmology, not oncology — creating unique supportive care gaps

melanoma.
patients
australia

Background: Clinical priorities for ocular melanoma patients



melanoma. patients australia

Background: Why a collaborative nursing model matters for ocular melanoma patient care

THE CHALLENGE

- Diagnosis and care pathways begin in ophthalmology centres, not oncology centres
- Fragmented care across ophthalmology, radiation physics, ocular oncology and medical oncology services
- Uncertainty, fear of recurrence and psychosocial distress from time of diagnosis and beyond treatment
- Rare Cancer = Isolation and need for self advocacy
- Impacts the consistency of delivery in psychosocial, navigation and survivorship support
- Introduction of neoadjuvant trials for primary stage OM
- Very few specialist nurses hold both ophthalmology and cancer nursing expertise

OUR RESPONSE

This model of care is not about duplicating roles - it's about connecting expertise

- Both nurses operate at top of scope
- Both address different but overlapping gaps in patient care
- Neither nursing role replaces the other
- Psychosocial, navigation and survivorship supports remain consistent for patients throughout their entire care pathway
- Enhanced education capabilities between nursing roles at a national level
- National, accessible support to a specialist melanoma services within the Australian Cancer and Nurse Navigation Program.

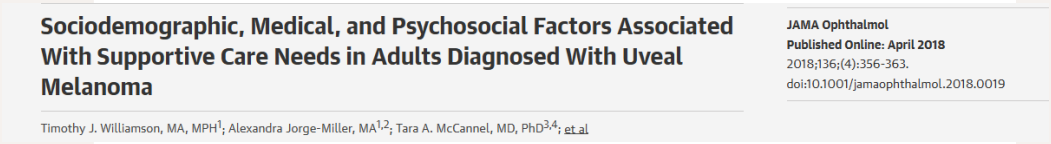
Holistic patient centered care and support beyond the clinic

melanoma. patients australia

Literature Evidence: To support a collaborative nursing model for ocular melanoma patients

UNMET SUPPORTIVE CARE NEEDS

- Williamson et al. (2018) JAMA Ophthalmology, 136(4), 356–363 (3)
- Prospective longitudinal study of 107 uveal melanoma patients



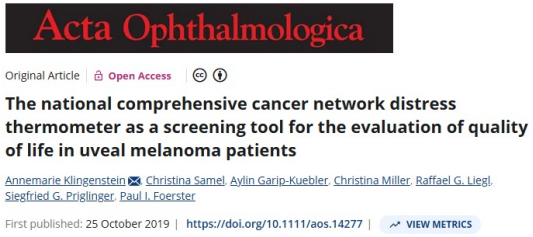
Sociodemographic, Medical, and Psychosocial Factors Associated With Supportive Care Needs in Adults Diagnosed With Uveal Melanoma

Timothy J. Williamson, MA, MPH[1]; Alexandra Jorge-Miller, MA[1,2]; Tara A. McCannel, MD, PhD[3,4]; et al

JAMA Ophthalmol
Published Online: April 2018
2018;136;(4):356-363.
doi:10.1001/jamaophthalmol.2018.0019

DISTRESS SCREENING IN PRACTICE

- Klingenstein et al. (2020) Acta Ophthalmologica, 98, p381–e387 (4)
- NCCN Distress Thermometer applied to 106 uveal melanoma patients



Acta Ophthalmologica

Original Article | Open Access

The national comprehensive cancer network distress thermometer as a screening tool for the evaluation of quality of life in uveal melanoma patients

Annemarie Klingenstein, Christina Samel, Aylin Garip-Kuebler, Christina Miller, Raffael G. Liegl, Siegfried G. Priglinger, Paul I. Foerster

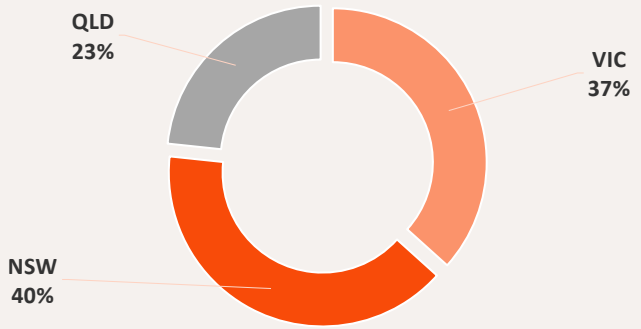
First published: 25 October 2019 | https://doi.org/10.1111/aos.14277 | VIEW METRICS

Together, these studies establish that uveal melanoma patients have significant, persistent psychosocial needs - and that validated screening tools exist to identify those in distress. A collaborative nursing model can bridge the gap.

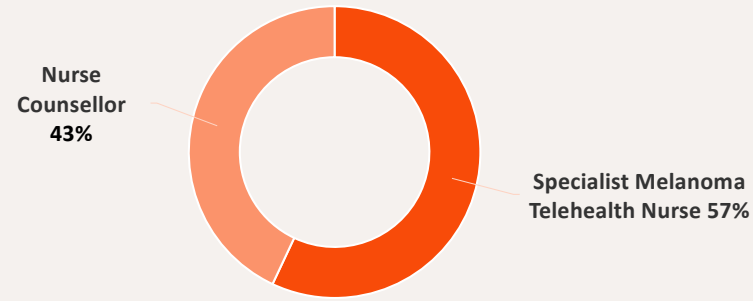
melanoma. patients australia

MPA Service Data Evidence (2026): To support a collaborative nursing model for ocular melanoma patients

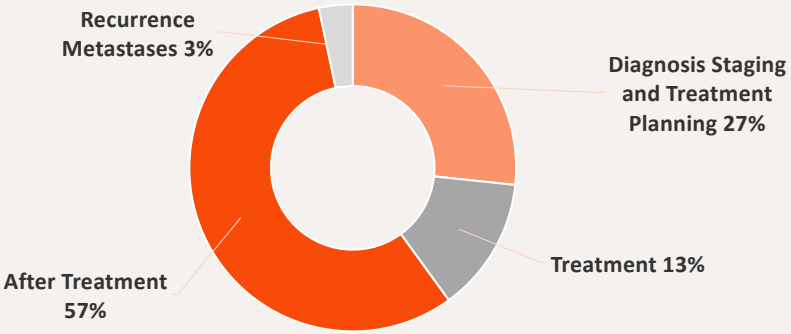
Melanoma Telehealth Specialist Nurse Consultations by State for ocular melanoma patients



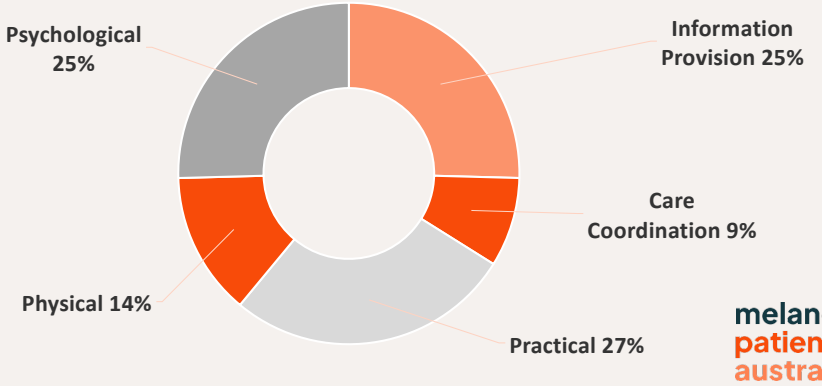
Melanoma Telehealth Specialist Nurse Consult Distribution for ocular melanoma patients



Key Transition Points for Specialist Melanoma Telehealth Nurse Support for Ocular Melanoma

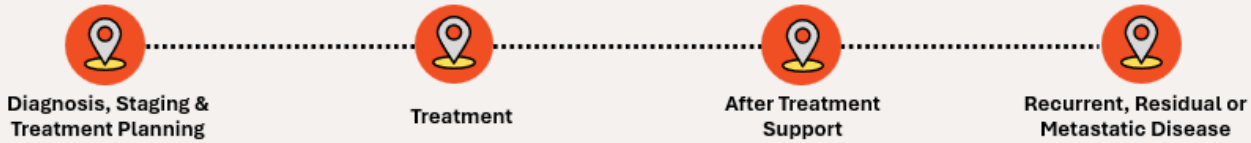


Type of Specialist Melanoma Telehealth Nurse Support for ocular melanoma



melanoma.
patients
australia

Design/Methods: Defining Two Specialist Nursing Roles



Clinical Ocular Melanoma Nurse

PRIMARY STRENGTHS

- Embedded in diagnostic & treatment setting
- Clinical education around plaque brachytherapy and surgical treatment
- Treatment coordination, monitoring and specialist follow-up
- Trusted first contact a from diagnosis to treatment and beyond
- The conduit for access to specialist melanoma supportive care

PATIENT

Specialist Melanoma Telehealth Nurse (Supportive Care)

PRIMARY STRENGTHS

- Longitudinal holistic nursing assessment across settings
- Psychosocial screening & transitions support
- Navigation, advocacy, practical supports
- Survivorship framing and sense-making
- Specialist melanoma knowledge related to Ocular Melanoma
- Accessible, FREE National Telehealth Nurse support

"These nurses don't do the same work — they meet the patient at different transition points in the care pathway."

Design/Method: A collaborative nursing approach to address patient reported needs in early survivorship

* Images are for illustrative purposes only and represent a generalised ocular melanoma diagnosis and treatment pathway

melanoma.
patients
australia

Design/Method: Case Study Reflection
Middle-aged female with unilateral ocular (uveal) melanoma

1. Optometrist

Suspicious lesion identified

2. General Ophthalmologist

Referred for further assessment and imaging

3. Specialist Ocular Oncologist

Specialist diagnosis of Ocular (Uveal) Melanoma

4. Treatment

Plaque radiation (Ruthenium Plaque Brachytherapy)

5. Surveillance and Follow Up

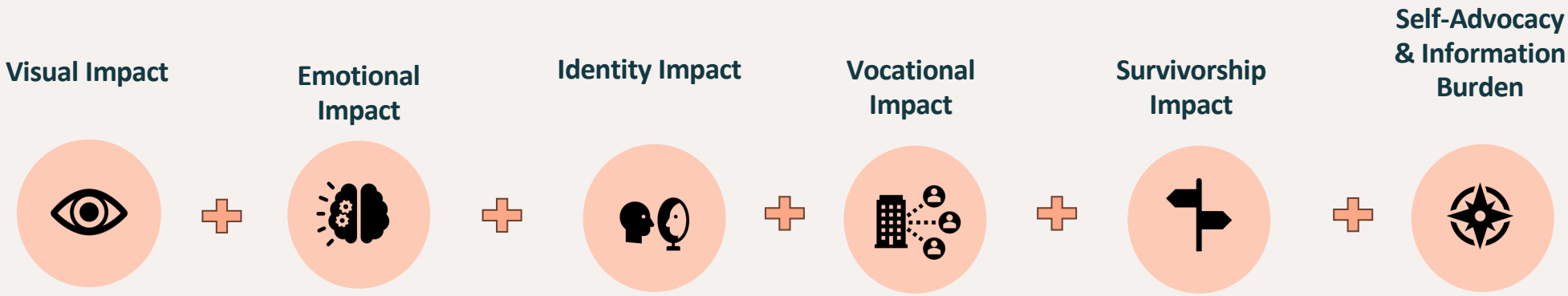
Ongoing monitoring, scans and clinical reviews

Patient referred into Melanoma Patients Australia's Specialist Melanoma Telehealth Nurse service - post treatment / early survivorship stage

melanoma.
patients
australia

Design/Method: Reflection of patient experience

Transition : Ater treatment support post treatment with plaque brachytherapy



Patient Quote post treatment ***"I HAD ocular melanoma or I HAVE ocular melanoma?"***

Recognising these themes in a holistic nursing care assessment helps to provide the right care at the right time.

melanoma. patients australia

Design/Method: A collaborative nursing approach to address patient reported needs

Patient Experience

- Uncertainty around recovery expectations – visual – and adjustment to 'new normal' following treatment
- Heightened anxiety and isolation emerging after initial diagnosis and treatment experience
- Difficulty managing post operative symptoms between clinical appointments
- Challenge of navigating follow up pathways (e.g MRI Surveillance) and transition to tertiary medical oncology follow up in early survivorship
- High information burden during initial diagnosis and treatment stage.
- Impact on Identity

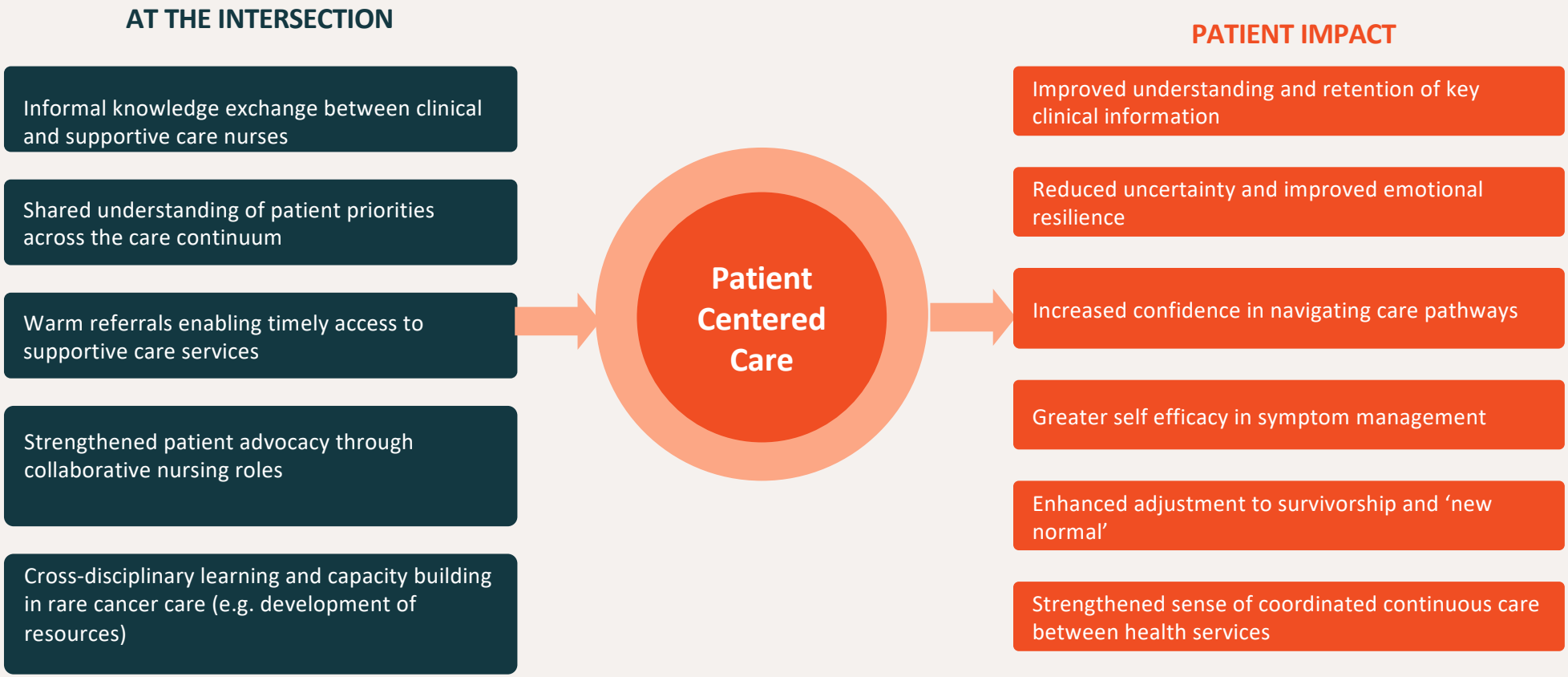
Collaborative Nursing Response

- Introduction of a supportive care nurse to reinforce information and provide ongoing support
- Ongoing psychosocial support alongside clinical follow-up
- Accessible telehealth support with a specialist melanoma nurse – complementing clinical care nursing
- Coordination and clarification of care pathway supporting patient understanding and adjustment in early survivorship stage
- Reinforcement and clarification of information post treatment to support patient understanding and recall
- Acknowledgment and validation of ocular melanoma patient experience

Patient experience is not a failure of clinical care.
These are predictable supportive care needs in a rare cancer pathway

melanoma. patients australia

Results: What changed when nurses collaborated for a rare cancer



Bridging the rare cancer gap. Connecting care. No patient left behind.

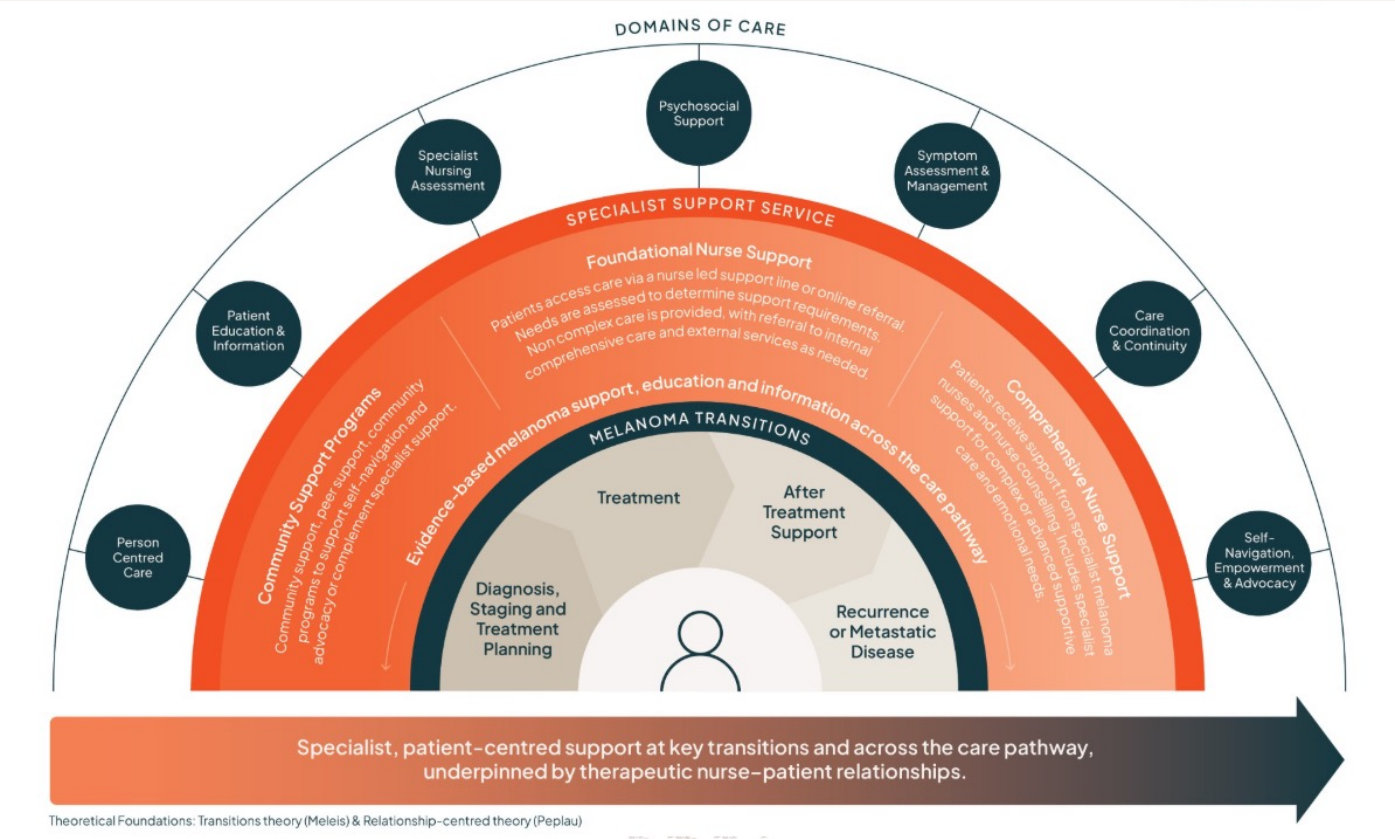
melanoma. patients australia

Conclusion: Collaborative hospital-clinic-telehealth model highlights the potential to advance supportive care for rare ocular melanoma patients

This model aligns to:

- **Melanoma Patients Australia's new Model of Care – Structured Specialist Nursing Process**
- *Meleis Transitions Theory - Patient vulnerability during diagnosis into post treatment*
- *Peplau's Interpersonal Theory – Trust, meaning making and empowerment*

Both nursing roles enact these theories – collaboration simply amplifies their effect



melanoma. patients australia

Why this collaborative model matters for funding and sustainability in a rare cancer

System Level Outcomes

- Prevents duplication of nursing roles
- Strengthens referral efficiency
- Extends specialist nursing reach in settings with limited funding capacity
- Builds rare cancer nursing capability nationally through shared learning opportunities
- Shared advocacy efforts to raise awareness of ocular melanoma in the community

Funding Logic

- Rare cancers need networked roles, not isolated posts
- Specialist telehealth nurse & clinical specialist nurse collaboration = scalable, equitable models of rare cancer patient care

Directly Links To

- Australian Cancer Plan (5)
- Australian Cancer Nurse Navigation Plan – Supportive care service objectives
- Melanoma Patients Australia Strategic Plan (1)
- 2024 CNSA Position Statement : Contribution of Cancer Nurses to Improve Outcomes for Individuals Impacted by Cancer (6)
- Rare Cancers Australia equity agenda (7))

melanoma. patients australia

Call to Action:
Embed Collaborative Nursing Models into Rare Cancer Frameworks

- Recognise and fund collaborative nursing models within rare cancer care frameworks
- Establish formal referral and communication pathways at a National level
- Embed supportive care earlier across the patient care pathway

"I'm already living with uncertainty – I shouldn't also have to coordinate my own care and advocate for things I don't even know what to ask for"

melanoma.
patients
australia

References

1. Melanoma Patients Australia. (2025). *Strategic plan 2025–2030*. https://melanomapatients.org.au/about-us/strategic-plan/

2. Cancer Council Australia. (2026). *Understanding eye melanoma*. https://www.cancercouncil.com.au/wp-content/uploads/2026/05/Understanding-Eye-Melanoma-2026.pdf

3. Williamson, T. J., Jorge-Miller, A., McCannel, T. A., Beran, T. M., & Stanton, A. L. (2018). Sociodemographic, medical, and psychosocial factors associated with supportive care needs in adults diagnosed with uveal melanoma. *JAMA Ophthalmology, 136*(4), 356–363

4. Klingenstein, A., Samel, C., Garip-Kuebler, A., Priglinger, S. G., & Foerster, P. I. (2020). Screening for predictive parameters requiring psycho-oncological intervention via the National Comprehensive Cancer Network distress thermometer in the follow-up of uveal melanoma patients. *Clinical Ophthalmology, 14*, 3813–3819

5. Australian Government Department of Health and Aged Care. (2023). *Australian Cancer Plan*. https://www.australiancancerplan.gov.au/

6. Cancer Nurses Society of Australia. (2024). Contribution of cancer nurses to improve outcomes for individuals impacted by cancer (position statement) https://www.cnsa.org.au/resource/contribution-of-cancer-nurses-position-statement-pdf.html

7. Rare Cancers Australia. (2025). Now it's personal: Access and equity for all. https://www.rarecancers.org.au/reports-submissions/now-its personal-access-and-equity-for-all/

melanoma.
patients
australia

Thank you and questions welcome

Peta.holly@melanomapatients.org.au

Melanoma Patients Australia

Make a Referral

Health Care Professionals

Model of Care

melanoma.
patients
australia