

# melanoma. patients australia

## A nurses role in supporting patients experiencing inequities and complexities of a RARE melanoma

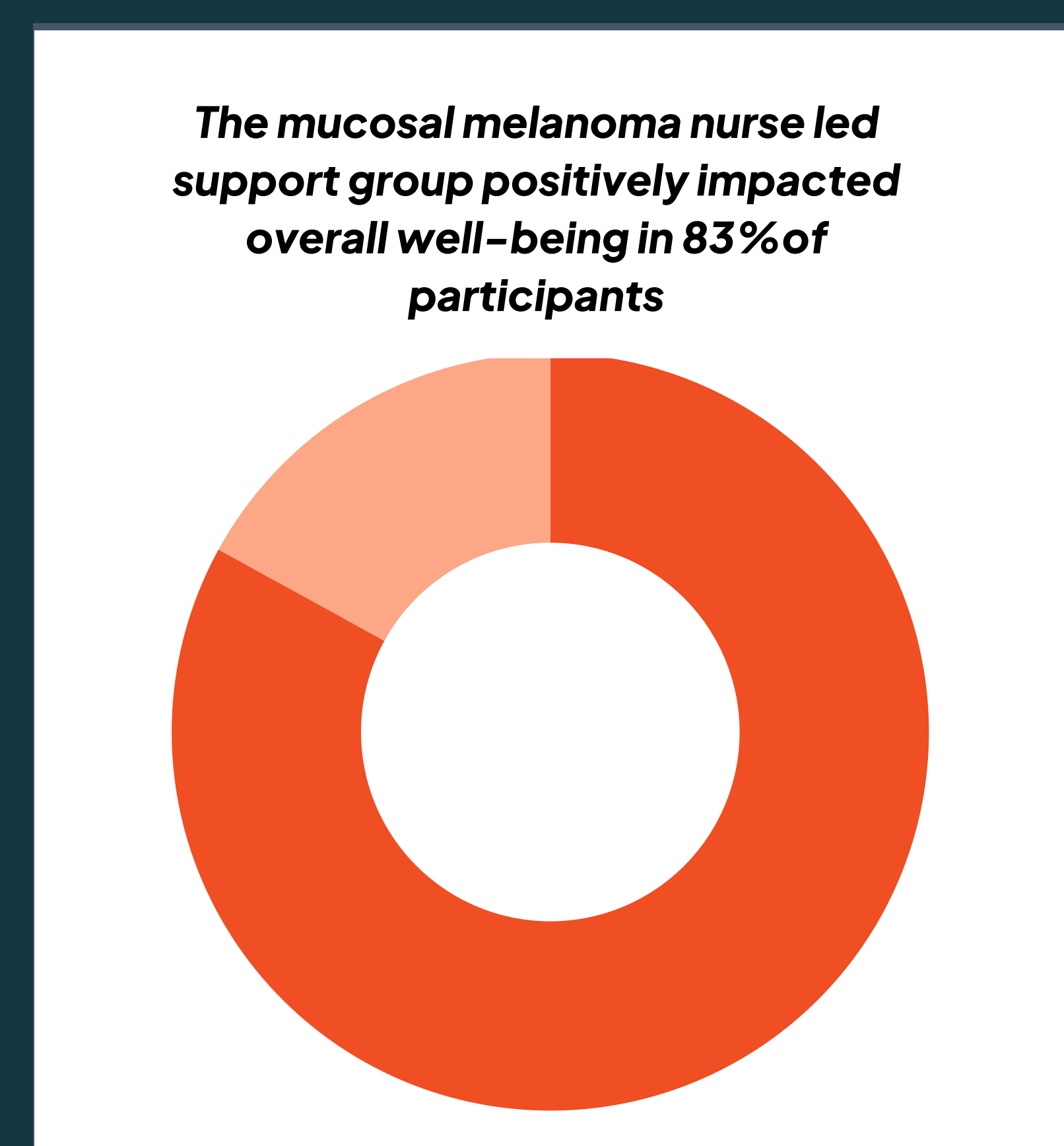
Mucosal melanoma represents less than 1% of melanoma cases. These patients experience complex physiological symptoms, high psychological needs, a poor prognosis and is associated with inequities including limited treatment options, no optimal care pathway and a lack of dedicated information and support. A nurse-led initiative was established in response to inequities and unmet needs reported by Australians with mucosal melanoma.

### Project

In response to feedback from patients living with mucosal melanoma, Melanoma Patients Australia commenced a project aimed to understand patient experiences and collect information about their unique needs to inform the delivery of dedicated support and information. Engaging with patients as partners, this project led to the development of national, nurse-led, patient-centred support and advocacy for patients living with mucosal melanoma.

### Method

- Data collection of patient-reported unmet needs and unique concerns
- Identification of the nursing care requirements, support and information needs for patients living with mucosal melanoma
- Scoping of existing support and information services



### Outcome

The project outcomes were:

- Identification of the unique physiological, psychological, and practical concerns faced by patients with mucosal melanoma
- Facilitated virtual peer support group for patients with mucosal melanoma
- Dedicated support and information from a specialist melanoma nurse
- Engaging with stakeholders to advocate for mucosal melanoma patients

### Melanoma Patients Australia have since committed to:

- Tailoring the telehealth nurse service to meet the unique needs identified
- A monthly virtual mucosal melanoma support group
- New dedicated rare melanoma website information
- Advocating for this rare type of melanoma

*The Mucosal Melanoma Support Group has made its participants feel validated, heard and not so isolated. It is a lonely road due to its rarity and it's difficult to find Doctors experienced in treating it. Our Nurse is leading the way in raising awareness on our behalf.*

*Judi, Mucosal Melanoma Support Group Member*

Given the positive self-reported outcomes of the support group participants and findings of the project, further work is required to raise awareness of the complexities associated with mucosal melanoma and to continue to ensure their unmet needs and inequities are understood and addressed, including ongoing dedicated funding to run vital supportive care options for ALL types of melanoma, including RARE types like mucosal melanoma.