

From past to present: Research priorities from a repeat melanoma community consultation

Karen Winch^{#1,2}, Jodie Kirkland^{#2}, Jules McNamara³, Kristy Barnes Cullen^{1,2}, Sonia Mailer^{1,2}, Tennille Lewin², Grant McArthur^{1,2}

- # Karen Winch and Jodie Kirkland contributed equally to this work
 1. Melanoma Research Victoria, Melbourne
 2. Peter MacCallum Cancer Centre, Melbourne
 3. Melanoma Research Victoria, Consumer Reference Group, Melbourne



CONSUMER-LED QUALITATIVE SURVEY UNCOVERING THE EVOLUTION OF RESEARCH PRIORITIES IN THE MELANOMA COMMUNITY OVER TEN YEARS.

Background:

- Melanoma, the deadliest form of skin cancer, is known as 'Australia's National Cancer'¹.
- Diagnosis rates are predicted to rise, with increasing numbers of Australians impacted¹.
- Consumer and community engagement in research priority setting improves relevance and outcomes of research and health services^{2,3}.
- Melanoma Research Victoria (MRV) is committed to embedding and amplifying lived-experience consumer perspectives into all areas of research⁴.
- In 2013 5-year survival was <10% for advanced disease and in 2021 it was >50%⁵.

Aims:

- Identify community research priority areas in 2013 and in 2023.
- Map the shift in attitudes.
- Consider findings for MRV strategic planning.

Methods:

- 2013: the MRV Consumer Reference Group developed a qualitative survey to identify melanoma community research priorities.
- Hard copy survey consisting open ended (n=4), multiple choice (n=2) and ranking questions (n=1), provided to attendees (Table 1) at the MRV Melanoma Community Forum (n=60).
- 2023: the survey emailed via SurveyMonkey to MRV researchers, consumer and participants (n=2877), Table 1.
- Descriptive thematic analysis approach was used to analyse the qualitative responses (Figure 1). Analyses conducted by MRV researchers, Health Services researcher and MRV melanoma consumer.
- Discrepancies resolved by consensus vote. Themes categorised and ranked into Research Priorities and Health Service Improvements.

Results:

	2013	2023
Respondents	60	171
Invited	60	2877
% responses	100	6
% patient	82	94
% carer	8	1
% clinician	5	1
% researcher	5	1

Table 1. Response by number and category

How have research priorities evolved for the melanoma community over ten years?

Leading priorities identified by thematic analyses

2013

2023

'Discovery projects that enable new drugs to be developed. These have the highest potential to improve cure rates' - P0144

'Definitely need more research as we have no definitive treatment' - P0423



Clinical research, new innovations & seeking a cure

'Basic Research to discover new treatment' - PT1621

'Continued and ongoing research. The changes in treatment over the last 10 or so years has been instrumental in allowing patients like me to still be alive' - PT1271

'We need more effective drug treatments. We also need increased capacity to give more people access to new medicines via clinical trials' - P0123

'Funding for new drugs needs to be accelerated; waiting for a clinical trial to begin may not provide the best outcome' - P0301

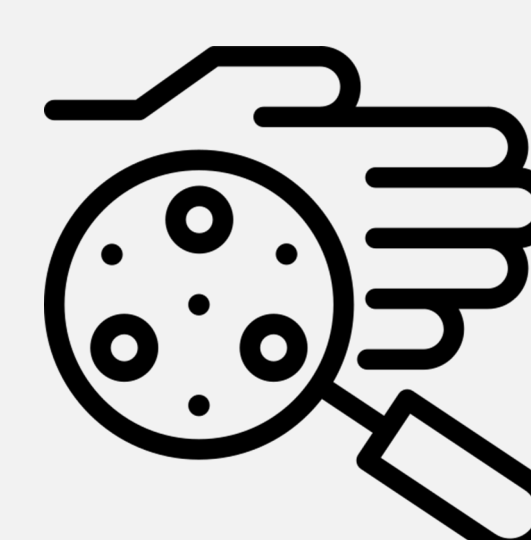


Refining treatments; focusing on recurrence, side-effects & clinical trials

'To find more non-invasive treatments' - PT1183

'Help to reduce the risk of colitis occurring when receiving immunotherapy' - PT0981

'Friendlier drugs to the body' - PT0152



Improving early detection & screening

'An ideal... would be a simple way to monitor and detect melanoma in its earliest stages, no matter where it is present in the body. Something like a breath test, non-invasive, easy to carry out, and widely available' - PT0023

'Research on early detection of melanoma' - PT0563



More effective prevention strategies

'Prioritize research that focuses on effective prevention strategies, including education about sun safety and reducing risk factors' - PT0353

'Better prevention, including novel active prevention treatments' - PT1622

Health Service improvement, future focus

In addition to identifying research priorities, strong themes emerged for Health Services investment in 2023.



Education & public health messaging

'I feel that there is not enough awareness in the community about the effects of sun exposure. Also, GP's give mixed messages not imparting confidence in finding melanoma' - PT0311

More public awareness campaigns, especially aimed at younger people... Informing people of the different types of melanoma, some with no colour changes - PT1303

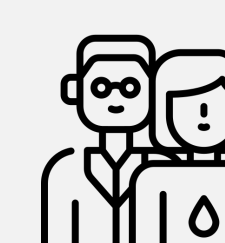


Equity: Access to screening, treatment & resources

'Greater access for people to get checked, particularly those with lack of health care services' - PT0163

'Making skin checks free under Medicare' - PT0272

'Care/ support access both in rural and urban centres' - PT1133



Survivorship

'Long-Term Survivorship: Investigate the long-term effects of melanoma treatments and develop strategies to improve the quality of life for long-term survivors' - PT0321

I would ensure a percentage (of funds) is directed to social/emotional research e.g. survivorship, supportive care, patient reported outcomes, anxiety etc - CL0013

Discussion:

This MRV consumer-led research identifies shifting attitudes and preferences of the melanoma community over time. The increase in 5-year survival for patients with advanced disease from 10% to over 50%, due to the implementation of PBS funded immune checkpoint blockade (2012) and targeted inhibitor (2013) systemic treatments, may account for the expansion in prioritising 'cure and new innovation' (2013) to include 'early detection and prevention' (2023). This research highlights the community's increased knowledge and awareness of the issues faced by melanoma patients. Participants expressed the need to consider more than an investment in research, with many identifying Health Service priority areas such as the need for innovative sun-safety public health messaging and awareness campaigns. Additionally addressing health equity disparities and investing in survivorship are important priorities for the current melanoma community.

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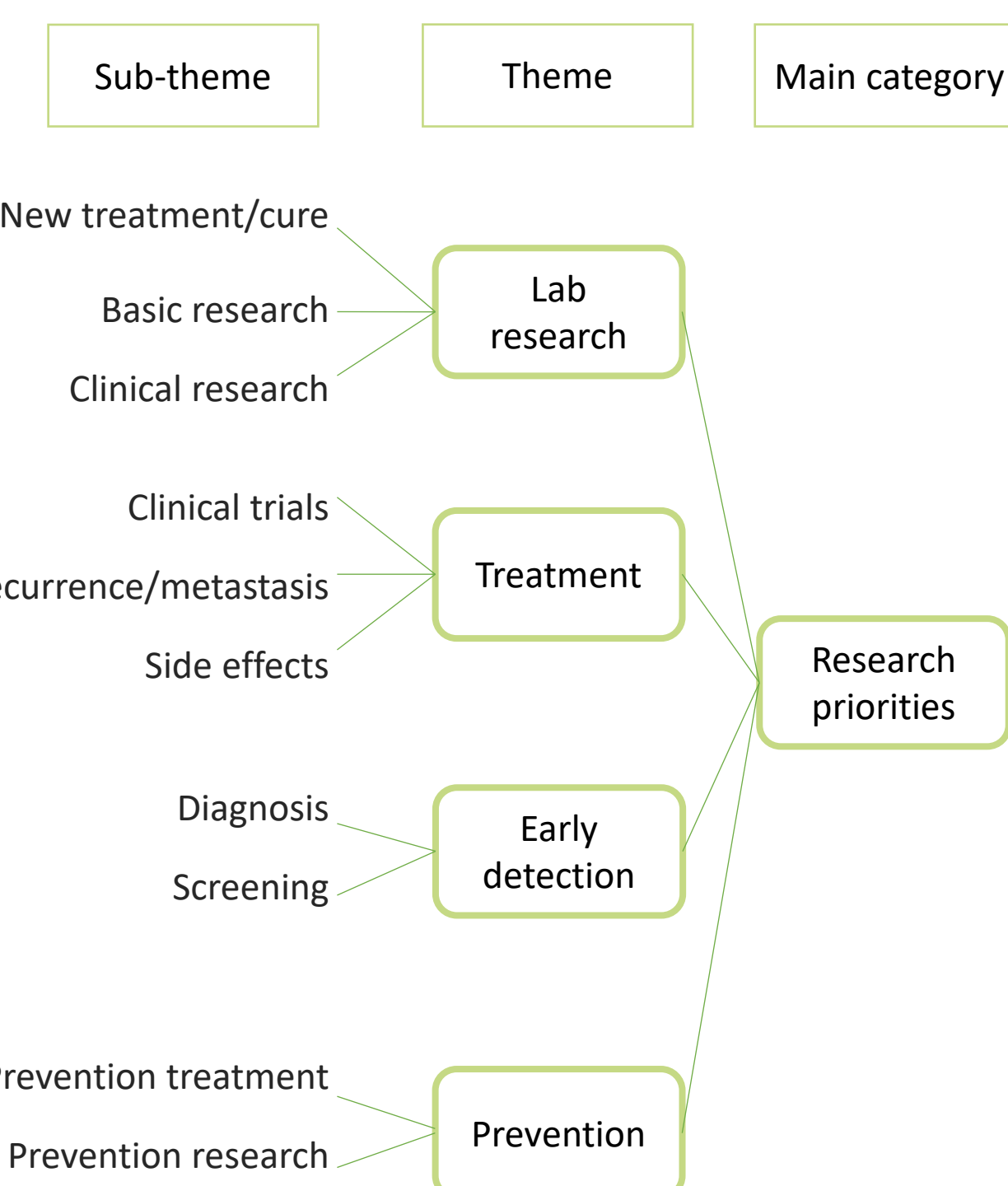


Figure 1. example of the thematic abstraction process

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