



Consumer and Community
Involvement Program



WAHTN
Western Australian Health Translation Network

HAVE YOU HAD SKIN CANCER?

Micro Community Conversation

SUMMARY REPORT



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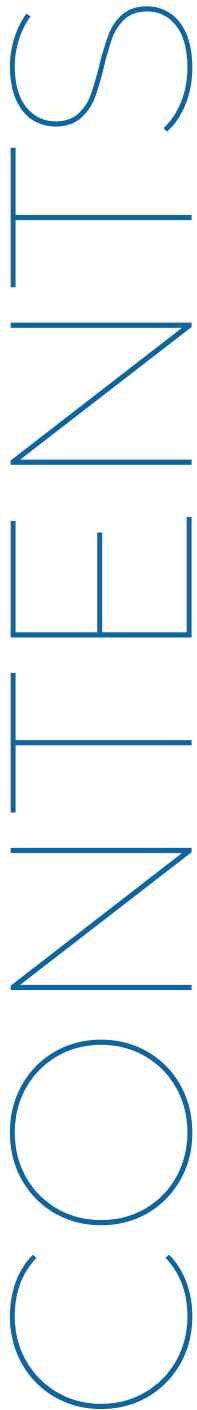
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March
2025



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ACKNOWLEDGEMENTS

Acknowledgement of Country

The WAHTN CCIP Program acknowledges the Aboriginal people of the many traditional lands and language groups of Western Australia. We acknowledge the wisdom of Aboriginal Elders, both past and present, and pay respect to Aboriginal communities of today.

Acknowledgement of Lived Experience

We acknowledge the importance and expertise of the lived experience voice of health consumers and carers. We recognise their involvement in making a difference in supporting health research and impacting the health and wellbeing of our communities.

We extend our heartfelt gratitude to the consumers and community members who shared their lived experiences of skin cancer.

We also thank the research team from Harry Perkins Institute of Medical Research and the University of Western Australia, Dr Lena Kranold and Assoc Prof Paul Stanwix, for their commitment to involving consumers in shaping the future of skin cancer research.



BACKGROUND

Dr. Lena Kranold and Associate Professor Paul Stanwix are leading a collaborative research project to develop a low-cost, portable probe for non-invasive skin cancer detection. By combining their expertise to apply this to the electrical properties of both healthy and cancerous skin tissue, this research team from the Harry Perkins Institute of Medical Research (HPI) and the University of Western Australia (UWA) is working towards the goal of creating a cost-effective, hand-held device. This device aims to distinguish between healthy, benign, and malignant skin lesions, including melanoma, without the need for invasive biopsies. The team will refine a prototype using advanced simulation software and laboratory models, followed by testing on excised tissue samples. This innovation aims to improve skin cancer screening in GP clinics, especially in rural areas, offering early detection and better patient outcomes, and alleviating pressure on the public health system.



THE CONSUMER AND COMMUNITY INVOLVEMENT PROGRAM

The Consumer and Community Involvement Program (CCIPProgram) is dedicated to embedding the voices of consumers and community members in health research. Established as part of the Western Australian Health Translation Network (WAHTN), the program works to ensure that research is shaped by lived experience and addresses real-world health challenges.

At the heart of the CCIPProgram is a team committed to building connections between researchers, consumers, and organisations. This team provides tailored support, guidance, and resources to ensure consumer involvement is an integral part of research design, implementation, and translation.

By championing consumer and community involvement at local, state, and national levels, the CCIPProgram continues to evolve, ensuring that health research is informed, shaped and guided by those with lived experience.



WHAT IS A MICRO COMMUNITY CONVERSATION?

A Micro Community Conversation (MCC) is a structured, small-group discussion designed to gather in-depth insights from a select group of people with lived experience of a particular health issue. Typically involving four to six participants, an MCC provides a focused and intimate setting for researchers to engage directly with consumers, utilising a structured conversation format.



A MCC may be an ideal consumer involvement approach when:

- A particular health condition or research topic makes it difficult to engage a larger group, such as when the condition is rare or affects a highly specific population.
- The topic is sensitive, requiring a smaller, more supportive environment for participants to feel comfortable sharing their experiences.
- Researchers are in the early stages of exploring a topic and need initial insights before determining how best to expand consumer involvement.

Key insights from an MCC may be used to inform future studies or serve as a stepping stone toward a full Community Conversation where broader community input is sought.

ABOUT THE SKIN CANCER MICRO COMMUNITY CONVERSATION

This Micro Community Conversation (MCC) explored the lived experiences of people who had been diagnosed with skin cancer to ensure that future research aligned with the priorities of those affected by this health condition. The session provided an opportunity for consumers to share their insights on the diagnostic journey, barriers to timely and accurate detection, and their perspectives on how a non-invasive skin cancer detection device could improve access, equity, and outcomes across diverse community settings.

The Micro Community Conversation was held on Thursday 20 March 2025, at Harry Perkins Institute, involving Dr Lena Kranold and Assoc Professor Paul Stanwix, CCI Coordinator Caroline Jones from the CCIProgram, and six consumers with lived experience of skin cancer. The researchers presented an overview of their backgrounds and previous research, outlined their research proposal for the development of a low cost, hand-held device for the detection of skin cancer, and acted as scribes for the subsequent discussion.



Lena Kranold



Paul Stanwix

PROMOTION

The Research Team worked with the CCIPProgram to recruit consumers who have lived experience of skin cancer to hear their thoughts on future research directions. Communications were shared across multiple channels.

Flyers and social media posts (X, Facebook, Instagram and LinkedIn) were shared across relevant networks, including consumer and related health service provider networks and community groups.

Consumers indicated their interest and were selected to achieve a diverse range of backgrounds, age, gender, ethnicity and lived experience, using the CCIPProgram's matching service.



WE WOULD LIKE TO HEAR FROM PEOPLE WITH A LIVED EXPERIENCE OF SKIN CANCER

MICRO COMMUNITY CONVERSATION

Researchers want to know your thoughts about skin cancer detection to guide the development of their research proposal. The team is exploring new technologies that will enable the development of a low-cost medical device to detect skin cancer early. Your lived experience of skin cancer will assist the research team to gain a better understanding of what is important and relevant to consumers. Your experiences, knowledge, understanding and expectations will shape and guide the direction of this research.

Experience required:

- A lived experience of skin cancer, ideally detected and treated within the last 10 years
- Comfortable sharing your health experiences initially via a phone conversation and then within a small group setting

A \$70 honorarium (gift card) is offered to attendees and light refreshments will be provided.

DATE:	Wednesday, 20 March 2025
TIME:	6-8pm (5:45pm registration for 6pm start)
LOCATION:	Nedlands, WA

SUBMIT AN EOI:
<https://bit.ly/3EAH5sD>

SCAN ME



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STRUCTURE AND PROCESS

The Micro Community Conversation was facilitated by Caroline Jones, CCI Coordinator from the CCIProgram, who guided participants through structured discussion questions. The context for the discussion was provided by Dr Lena Kranold, who shared background information about the research team, her previous research into the development of a ‘Smart bra for detection of breast tissue changes’ and the current research progress into the development of a device for detection of skin cancer. Dr Lena Kranold assisted in capturing insights by taking de-identified notes.

The discussion was designed to prioritise consumer voices, and ensure the focus was on lived experience. The researchers were present to both listen and capture insights. Researchers sought additional information or clarification where necessary, ensuring the emphasis remained on building understanding of the lived experience perspective and providing space for consumers to share their experiences.

Consumers were presented with four questions to discuss:

1. What was your experience around the diagnosis of your skin cancer/s and how could this have been improved?
2. In the research being explored, the team is trying to develop a low-cost skin cancer probe that can identify different forms of skin cancer without having to excise the tissue. How do you think this research will have an impact?
3. The goal of this research is to provide a tool that can be used in GP practices to support earlier diagnosis of skin cancer. Do you think it is practical to target GP clinics specifically rather than specialist clinics?
4. Initial concept to device is a long journey. What do you think the researchers need to be aware of when moving through the journey into clinical trials etc.? What needs to be kept in mind to keep this useful and impactful?

Each question was allocated 20 minutes for discussion. The comments, feedback, and suggestions were captured by the scribe and are presented in the following pages of this report.



KEY INSIGHTS OF THE MICRO COMMUNITY CONVERSATION



Challenges at the Point of First Contact: GP Settings

Most consumers initially sought medical advice from their GP based on personal concerns about suspicious skin changes. However, these consultations were often marked by misdiagnosis, dismissal of concerns, or delay due to a necessary referral to a dermatologist. This pathway frequently involved multiple steps and extended waiting periods, leading to frustration and, in some cases, delayed detection and treatment of cancer. These experiences highlight the limitations of current diagnostic practices in general practice and strongly support the idea of a tool that can aid GPs in making earlier, more accurate diagnoses at the point of care.



Systemic Barriers to Access and Equity

Consumers described significant barriers to accessing a timely and appropriate skin cancer diagnosis. These included lengthy waitlists for dermatologists, difficulties navigating referrals, the cost of care, and logistical issues in rural or remote areas. People with disabilities, neurodiverse individuals, and those with complex health needs were identified as particularly underserved under the current model. These access challenges suggest that decentralising diagnostic capacity—with appropriate safeguards—could improve equity and reduce missed or delayed diagnoses.



Potential of a Non-Invasive Diagnostic Tool to Bridge Gaps

A portable, non-invasive device with a high degree of accuracy was viewed as a potentially transformative innovation, particularly if it could be made available in GP clinics or community settings such as pharmacies or aged care facilities. Consumers saw great promise in its ability to reduce unnecessary biopsies, lower psychological and physical trauma, and provide a less intimidating alternative to traditional skin checks—especially for vulnerable groups. However, its success hinges on reliability, appropriate training for use, and integration into clinical practice.



Building Trust and Transparency

Consumers acknowledged the value of the proposed technology but also raised thoughtful concerns about how it will be introduced, trialled, and communicated. Key considerations included managing public expectations, ensuring that accuracy levels are made clear, and communicating the role of the device in relation to existing diagnostic processes (e.g. how it compares to biopsy results). There was general willingness to support clinical trials, particularly from those with lived experience, but transparency—especially around what trial participants can expect—was seen as critical for maintaining trust and uptake.

KEY DISCUSSION POINTS OF THE MICRO COMMUNITY CONVERSATION

Theme	Consumer Comments
Diagnosis Accuracy and Role of Specialist Care	• Misdiagnosis of first melanoma to most recent over 30 years very different. • Choice of doctor makes all the difference – misdiagnosed BCC as blackhead. • Dermatologists act right away and have better accuracy. • Untrained people do biopsies more often and they return negative. • First biopsy showed benign results – nodular melanoma developed on the same site 5 years later.
Health System Challenges and Wait Times	• Wait list for dermatologist is too long. • Many different steps to go through. • GP was suspicious and put through referral to dermatologist, with 3 months wait initially. • There are not enough dermatologists or highly trained. • Patients have to project manage their own health care professionals which is really challenging.
Barriers for Vulnerable Groups	• Naked examination is challenging for abuse survivors creating a barrier to screening. • People with disabilities and chronic health issues are underserved by current screening. This includes patients on the spectrum. • Portability of device to come to the patient, such as in aged care settings.
Potential Impact of New Technology	• Potentially massive impact. • Could lead to more frequent check-ups. • Could have great impact in rural and remote practices. • Removes objectivity. • Portability can be a great advantage.
Concerns About Implementation and Safety	• How would the training for all these entry-level healthcare practitioners work? • Would there be a push-back from dermatologists? • At what level of accuracy would people accept this? Maybe 80%? • Would you be comfortable to trust this device over a biopsy? • Apart from misdiagnosis, what harm could it do?
Opportunities for Access and Innovation	• Untapped market in molescan clinics. • Multicultural women's health services might be a good target. • Special schools and institutions for people with disabilities? • Skin checks at local swimming pools? • Pharmacy could also be great... would require a closed room to ensure privacy.
Importance of Clear Communication and Next Steps	• Bad news needs to be followed up immediately with appointment to reduce anxiety and fears. • Managing expectations of what are the next steps is essential before doing the instant diagnosis. • Would you be okay not being told the result of the clinical trial scan? Depends on how it's framed. • Needs to be clearly communicated that clinical trial results will not be communicated.

MICRO COMMUNITY CONVERSATION QUESTIONS AND RESPONSES

ATTENDEE INSIGHTS

The following pages contain the responses and thoughts shared by attendees at the Micro Community Conversation

QUESTION 1

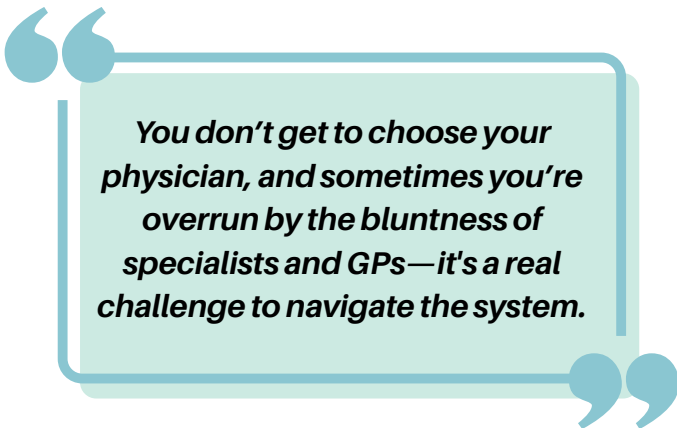
WHAT WAS YOUR EXPERIENCE AROUND THE DIAGNOSIS OF YOUR SKIN CANCER/S AND HOW COULD THIS HAVE BEEN IMPROVED?

Prompts: For diagnosis, what could have been done differently?
How could your diagnosis have been confirmed faster?

Participants shared a range of experiences related to the diagnosis of their skin cancers, highlighting the challenges of misdiagnosis and the crucial role of the healthcare provider in ensuring accurate and timely detection. Many reflected on the improvement in the quality of diagnosis over the years, especially with the increasing confidence and training of GPs and specialists. However, issues such as long wait times for specialist appointments, misdiagnoses, and the need for patients to advocate for their own health care were common themes. Participants emphasised the need for more efficient access to dermatologists and for tools that could improve diagnostic accuracy and reduce unnecessary biopsies.

Key insights included:

- Misdiagnoses, especially in the early stages of skin cancer detection, remain a significant concern. In particular, there is a large variation in the accuracy of GPs and specialists.
- The long wait times for specialist referrals and the need for patients to navigate the healthcare system themselves are major barriers to timely diagnosis.
- Confidence in diagnosis has improved, but patients still experience stress and anxiety due to the complexity of diagnosis and follow-up procedures.
- Dermatologists are generally more accurate in identifying skin cancer, but untrained practitioners sometimes conduct unnecessary biopsies or miss key signs.
- The importance of quick follow-up after diagnosis to reduce anxiety and ensure appropriate care is critical.



You don't get to choose your physician, and sometimes you're overrun by the bluntness of specialists and GPs—it's a real challenge to navigate the system.

QUESTION 2

IN THE RESEARCH BEING EXPLORED, THE TEAM IS TRYING TO DEVELOP A LOW-COST SKIN CANCER PROBE THAT CAN IDENTIFY DIFFERENT FORMS OF SKIN CANCER WITHOUT HAVING TO EXCISE THE TISSUE. HOW DO YOU THINK THIS RESEARCH WILL HAVE AN IMPACT?

Prompts - Can you think of potential problems with this technology?

Participants expressed that the development of a low-cost skin cancer probe has the potential for a significant impact. The tool could increase accessibility by reducing barriers like cost and wait times for specialist appointments, particularly in rural and remote areas. It was also noted that the tool could be used at entry levels, such as by nurses or in pharmacies, expanding access even further. There was consensus that better accessibility would lead to more frequent check-ups, earlier detection, and potentially fewer unnecessary biopsies. However, participants also raised concerns around how training for these new entry-level health professionals would work and the possible push-back from dermatologists.

Key insights included:

- A low-cost skin cancer probe could dramatically improve access to skin cancer detection, especially for underserved populations, including those with disabilities and chronic health conditions.
- The tool's portability and potential for use in pharmacies could reduce access barriers, but privacy concerns would need to be addressed.
- The impact could be significant in rural and remote areas, where access to specialists is limited.
- There is a concern about how the training for non-specialist users, such as nurses or pharmacists, would be implemented and whether dermatologists might resist the tool.
- More frequent screenings are likely to occur, improving early detection and potentially reducing the number of unnecessary biopsies.
- Education on skin cancer prevention needs to continue improving, especially in underrepresented communities.

If it's really accurate, even someone without specific accreditation could use it, like a pharmacy, and that could make a huge difference in access.

QUESTION 3

THE GOAL OF THIS RESEARCH IS TO PROVIDE A TOOL THAT CAN BE USED IN GP PRACTICES TO SUPPORT EARLIER DIAGNOSIS OF SKIN CANCER. DO YOU THINK IT IS PRACTICAL TO TARGET GP CLINICS SPECIFICALLY RATHER THAN SPECIALIST CLINICS?

Prompts: How do you think this would impact people with skin cancer in rural settings?
What are some reasons this might be a good idea?
Why might this not work?
Do you think this would improve diagnostic outcomes for people with skin cancer?

Participants were largely in agreement that targeting GP clinics is a practical approach. Many noted that GPs are often the first point of contact, but the accuracy of diagnosis can be inconsistent. There was strong support for adding nurse practitioners and exploring other avenues such as pharmacies and multicultural health services to broaden access. Cost was identified as a critical factor, but it was also highlighted that preventative services could be more cost-effective than dealing with the consequences of melanoma.

Key insights included:

- GP clinics should be targeted, as they are often the first point of contact for patients, though diagnoses can be inconsistent.
- The inclusion of nurse practitioners in the diagnostic process could improve early detection rates.
- The tool could be extended to pharmacies, though privacy and trust issues must be considered.
- The cost factor is a major consideration, but early detection is likely more cost-effective than treating advanced melanoma.
- Molescan clinics, multicultural women's health services, and even institutions for people with disabilities are potential untapped markets.
- Skin checks could be incorporated into community spaces like swimming pools, expanding accessibility.

GPs are the first point of contact, but diagnosis is hit and miss, so providing support in that setting could make a huge difference.

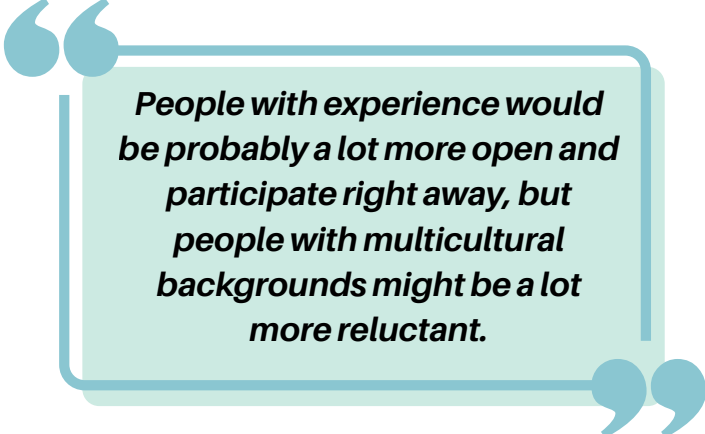
QUESTION 4

INITIAL CONCEPT TO DEVICE IS A LONG JOURNEY. WHAT DO YOU THINK THE RESEARCHERS NEED TO BE AWARE OF WHEN MOVING THROUGH THE JOURNEY INTO CLINICAL TRIALS ETC.? WHAT NEEDS TO BE KEPT IN MIND TO KEEP THIS USEFUL AND IMPACTFUL?

Participants discussed the challenges researchers should be aware of as the device progresses to clinical trials. A key point was the need to remain adaptable to rapid changes in technology, regulations, and skin cancer presentation. Clear communication with participants about the trial process, particularly around the handling of results, was also emphasised as critical for engagement.

Key insights included:

- Rapid technological and regulatory changes require constant adaptation.
- The device must account for varying skin types and cancer presentations.
- Individuals from multicultural backgrounds may be hesitant to join clinical trials, so trust-building is crucial.
- Clear and transparent communication about trial procedures and results is necessary to ensure participant confidence.
- Providing trial results alongside biopsy outcomes could improve engagement and reduce anxiety.
- Researchers should consider potential reluctance from participants in clinical trials and ensure the process is framed in a way that is inclusive and accessible.



People with experience would be probably a lot more open and participate right away, but people with multicultural backgrounds might be a lot more reluctant.

EVENT SUMMARY

The Micro Community Conversation provided a rich and focused discussion, allowing researchers to explore specific lived experiences of skin cancer diagnosis in depth. Participants found the session valuable, with many expressing appreciation for the opportunity to contribute directly to research and a willingness to continue their involvement in the future. This event fostered a deeper understanding of the real-world challenges people face when it comes to early detection and diagnosis of skin cancer, as well as the potential impact of the proposed tool.



NEXT STEPS

- The research team will use these insights to refine research planning, ensuring that the tool's development aligns with patient needs and experiences.
- Future consumer involvement will continue to be a priority, with ongoing efforts to engage consumer in the development process and ensure their perspectives shape the tool's design and functionality.

WHAT'S NEXT FOR THIS PROJECT?

We will use the information from the Micro Community Conversation to:

- Focus our efforts in fine-tuning the prototype of the skin cancer detection probe on lab models to ensure its effectiveness and accuracy in detecting various forms of skin cancer in real-life settings.
- Findings from this MCC will be integrated into funding proposals to support further research and development.

WANT TO KNOW MORE?

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