Consumer and Community Involvement Program

WAHTN
Western Australian Health Translation Network

LIVING WITH SKIN CANCER IN RURAL OR REMOTE WA

Micro Community Conversation

SUMMARY REPORT

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THE UNIVERSITY OF WESTERN AUSTRALIA

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ACKNOWLEDGEMENTS

Acknowledgement of Country

The WAHTN CCIProgram 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

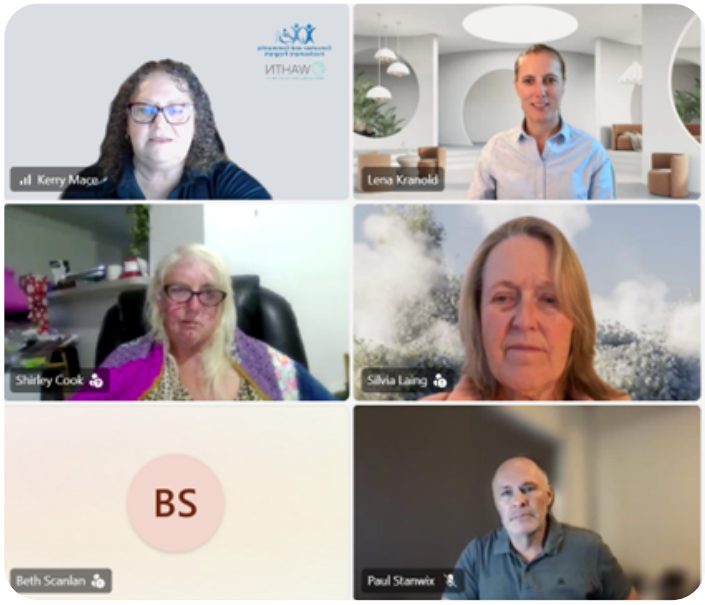
We acknowledge the importance and expertise of the lived experience voice of health consumers and carers. We recognise their involvement in making a difference in supporting health research and impacting the health and wellbeing of our communities.

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 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 approach 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.



To complement the early stages of the research, a Micro Community Conversation was held in March 2025 to gather consumer perspectives on skin cancer detection and the potential role of this emerging diagnostic technology. This Conversation provided valuable insights into community understanding of skin cancer risk, experiences with diagnosis and screening, and expectations around new, non-invasive tools. Attendees shared views on accessibility, trust, and practical considerations for use in primary care, highlighting the importance of affordability, ease of use and clear communication. The learnings from this initial Micro Community Conversation helped to inform the ongoing direction of the research and reinforced the need to consider how new technologies may be experienced differently across diverse settings and populations.

THE TEAM

Dr Lena Kranold is a researcher based at the Harry Perkins Institute of Medical Research and the University of Western Australia. Her work focuses on the development of innovative, non-invasive diagnostic technologies, with a strong interest in improving early detection and access to care. Dr Kranold's research explores how the electrical properties of human tissue can be used to distinguish between healthy and cancerous cells.

Associate Professor Paul Stanwix is a researcher at University of Western Australia with expertise in engineering, measurement science, and the development of advanced sensing technologies. His work focuses on designing and applying novel measurement systems to better understand and detect complex physical phenomena.

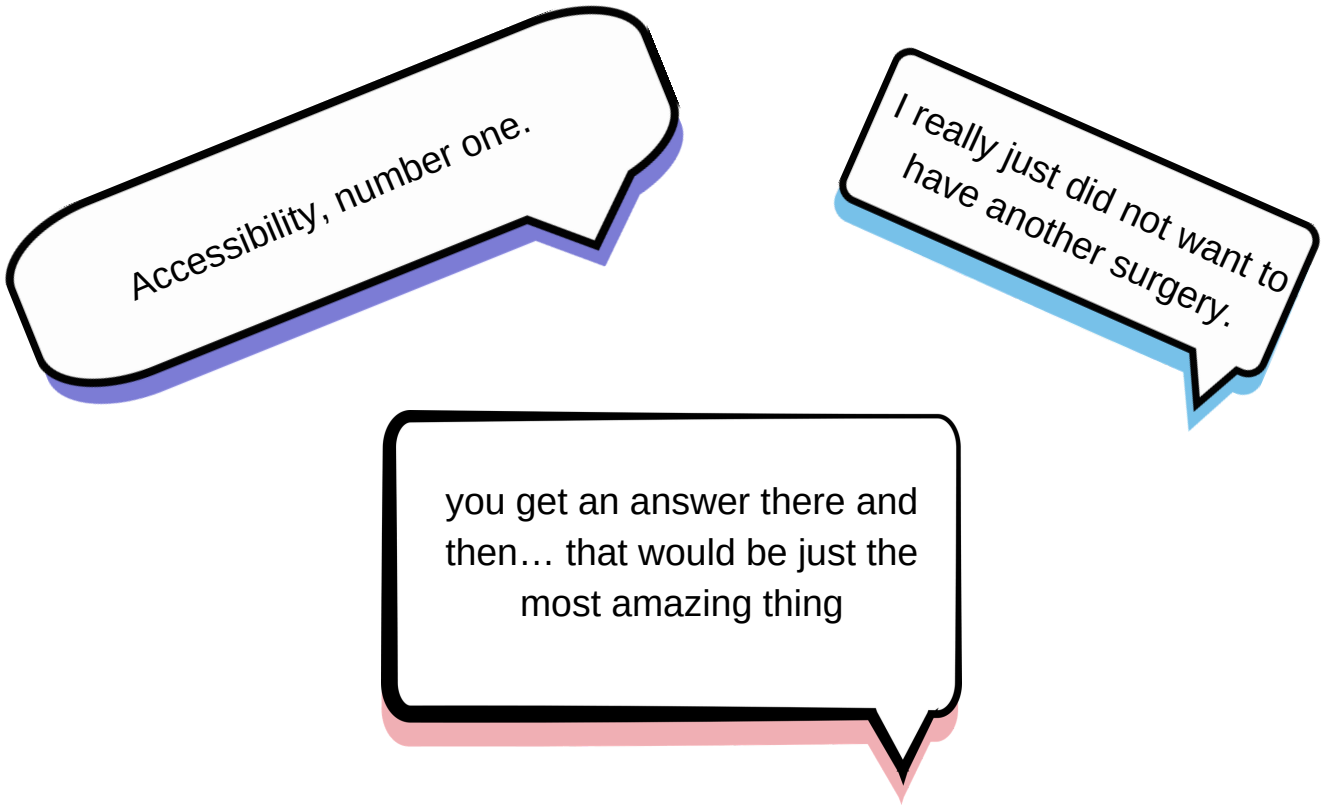
The Consumer and Community Involvement Program (CCIProgram), part of the Western Australian Health Translation Network (WAHTN), supports the meaningful involvement of consumers and community members in health and medical research. The program works to ensure that research is shaped by lived experience and addresses real-world health priorities.

ABOUT THE MICRO COMMUNITY CONVERSATION

A Micro Community Conversation is a small, structured discussion designed to gather insights from a highly targeted group of individuals (4-6 participants) with specific lived experiences. The format is designed to be intimate, flexible, and highly focused, making it particularly useful for discussing niche, sensitive, or emerging health research areas.

This Micro Community Conversation built upon last year's Conversation which 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 Tuesday 24 March 2026, and included three consumers from rural Western Australia and was led by Kerry Mace from the Consumer and Community Involvement Program.



PROMOTION

The Research Team worked closely with the CCIProgram to recruit members of the Australian community who reside in rural or remote WA and had lived experience of skin cancer to hear their thoughts on skin cancer detection, access to care in rural settings, and the potential role of a low-cost, non-invasive diagnostic device within primary care. We shared promotional communications across multiple channels.

Flyers and social media posts (Twitter, Facebook, Instagram and LinkedIn) were posted and circulated around relevant networks, including consumer and/or related health service provider networks and community groups.

STRUCTURE AND PROCESS

The Micro Community Conversation was facilitated by Kerry Mace, CCI Coordinator from the CCIProgram, who guided attendees 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 three questions:

- 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?

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

Delays and diagnostic uncertainty are causing harm

Attendees described diagnostic pathways characterised by delays, misdiagnosis, and long waiting periods for biopsy and results. These delays were not only distressing but, in some cases, led to disease progression and the need for more extensive treatment. Repeated procedures due to unclear margins further compounded physical and psychological burden. This highlights a clear need for more timely and accurate diagnostic approaches.

Strong support for immediate, point-of-care diagnosis in primary care

Attendees expressed clear support for a diagnostic tool that could provide immediate results within GP and community-based primary care settings. The ability to receive “an answer there and then” was seen as highly valuable in reducing uncertainty, supporting earlier decision making, and avoiding unnecessary or repeated procedures. There was strong endorsement for the tool to be used in primary care, with potential to improve both early intervention and referral pathways.

Accessibility barriers in regional areas drive inequity in care

Access to care was identified as a major challenge for attendees living in regional areas, with barriers including limited GP availability, difficulty accessing specialists, high out-of-pocket costs that influence care decisions, and workforce instability. These factors contributed to delays in diagnosis and treatment, and often required individuals to actively advocate for their own care when concerns were not initially acted upon. Improving accessibility is critical to achieving more equitable health outcomes, particularly in rural and remote communities.

KEY DISCUSSION POINTS OF THE MICRO COMMUNITY CONVERSATION

Theme	Consumer Comments
Accessibility as the overarching priority	• "Accessibility, number one." • "all of my health care has been based on my ability to either pay my way through or fight my way through the crowd."
Value of earlier, point-of-care diagnosis (probe)	• "you get an answer there and then… that would be just the most amazing thing" • "they can just do it there and then… and you can get it treated then" • "it would give me more reassurance that I'm being viewed correctly."
Access barriers in regional areas (GPs and specialists)	• "it's really hard to access specialist clinics." • "it's not easy to get into a GP clinic… you've got to go on a waiting list." • "we have a high, very high turnover of doctors here."
Financial burden and impact on care decisions	• "the financial cost to us is real as well. Very real." • "we're actually considering… driving to Perth… so that we get professional care."
Emotional impact and fear associated with diagnosis	• "it's extremely shocking to get a melanoma diagnosis… and it's very scary." • "that was a very, very hard six weeks for me."
Not being listened to and need for self advocacy	• "I just could not get them to listen to me." • "you have to be your own advocate."
Repeat procedures	• "I really just did not want to have another surgery." • "the second surgery was very traumatic actually."
Delays, misdiagnosis and system failure in diagnosis	• "they all just kept saying, it's just an infection." • "it took… about nine months… before they even decided to do this CAT scan." • "not having to wait for 10 or 14 days for a result… that would be just the most amazing thing"

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?

Attendees engaged in a detailed discussion on their experience around the diagnosis of skin cancer and how this could be improved. Key insights included:

Delays and inefficiencies in diagnostic pathways - Attendees described prolonged timeframes between initial presentation, biopsy, results, and definitive treatment. Delays were exacerbated by clinician availability, including periods where treating GPs were on leave, resulting in extended waiting periods and uncertainty.

Incomplete excision and the burden of repeat procedures - Multiple attendees described undergoing repeated surgeries due to inadequate margins at initial excision. This resulted in increased physical and psychological burden, including more invasive follow up procedures and, in some cases, hospital stays. The need to return multiple times for treatment was a significant source of distress.

Harm associated with delayed or missed diagnosis - Attendees described experiences where diagnosis was significantly delayed despite repeated presentations. In one case, a lesion was repeatedly diagnosed as an infection over a period of months before further investigation confirmed cancer, resulting in more extensive treatment requirements. These experiences highlight the potential for diagnostic delay to lead to disease progression and increased clinical risk.

Not being listened to and the need to self advocate - A strong and consistent theme was the need for attendees to advocate for their own care. This included insisting on biopsy, requesting referral, or challenging initial clinical assessments. Attendees described frustration when concerns were dismissed or not taken seriously, particularly when symptoms persisted or worsened over time.

Variability in clinical capability and reduced confidence in care - Attendees reported inconsistent experiences across clinicians, particularly within skin clinics staffed by GPs with varying levels of experience. This variability contributed to reduced confidence in diagnostic accuracy and, in some cases, influenced decisions to seek more senior clinicians or travel to metropolitan services for care.

MICRO COMMUNITY CONVERSATION QUESTIONS AND RESPONSES

QUESTION 1 (CONT)

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

Impact of regional location on access and decision making - Attendees living in regional areas highlighted additional challenges, including limited access to experienced clinicians, high turnover of GPs, and difficulty accessing specialist services. These factors contributed to delays in diagnosis and treatment, and in some cases prompted consideration of travelling to metropolitan areas to access more comprehensive care.

Emotional impact of diagnosis and uncertainty - The process of receiving a melanoma diagnosis was described as frightening and distressing, particularly for those with a family history of skin cancer. Waiting for biopsy results, undergoing multiple procedures, and uncertainty around outcomes contributed significantly to psychological burden.

Barriers to specialist access and affordability - Attendees noted that referral pathways created delays, particularly when GPs were reluctant to refer. Direct access to specialists without referral was not considered financially viable, limiting timely escalation of care. Cost and availability of services in regional areas further compounded these challenges.

One attendee expressed, “I really just did not want to have another surgery,” highlighting the distress associated with repeated procedures and the desire for more definitive treatment at the first intervention.

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?

Attendees engaged in a detailed discussion on the potential impact of a low cost skin cancer probe that could identify different forms of skin cancer without the need for excision.

Key insights included:

Value of immediate, point of care information - Attendees described the potential for the probe to significantly improve early decision making by providing greater certainty during the initial consultation. This was seen as a shift from reliance on visual assessment alone, enabling more informed and timely clinical decisions. Immediate results were considered highly valuable in reducing uncertainty and supporting next steps in care.

Potential to reduce unnecessary procedures and repeat surgeries - Attendees highlighted that improved accuracy at first presentation could support better identification of lesions requiring excision and clearer margins. This may reduce the need for multiple procedures, which were described as both physically and emotionally burdensome, and may also reduce associated surgical risks.

Emotional reassurance and reduced uncertainty - The ability to gain clearer information earlier in the diagnostic process was seen as highly reassuring. Long waiting periods between procedures and results were described as mentally and emotionally taxing, particularly where there was awareness of potential disease progression during this time.

Concerns regarding safety and cancer spread - While supportive of the innovation, attendees raised concerns about whether use of the probe could disturb cancerous tissue and increase the risk of spread if not followed by appropriate treatment. This reflects a need for clear communication about how the technology works and its safety profile.

Improved access and earlier diagnosis in primary care - Attendees noted that having the probe available in general practice could reduce reliance on specialist referral pathways, which were described as difficult, delayed, and at times inaccessible. The ability for GPs to diagnose earlier was seen as particularly beneficial in regional settings where access to specialist care is limited.

Financial benefits and reduced burden of ongoing care - Attendees described the cumulative financial impact of frequent follow up appointments, biopsies, and histology, many of which are not fully covered by Medicare. The probe was seen as having potential to reduce unnecessary visits and support more targeted monitoring, thereby reducing cost burden over time.

QUESTION 2 (CONT)

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??

Supporting more equitable access to care - Concerns were raised about affordability of current skin cancer services, with limited access to bulk billing clinics in regional areas. A low cost diagnostic tool was viewed as a potential way to improve equity of access, particularly for those who may otherwise delay or avoid care due to cost.

Increased confidence in monitoring and decision making - Attendees described uncertainty around lesions being “watched” over time, and whether earlier action should be taken. The probe was seen as providing clearer guidance on which lesions require intervention versus monitoring, supporting both clinicians and patients in decision making.

Potential for broader application of the technology - Attendees expressed interest in whether the technology could be applied beyond skin cancer, reflecting enthusiasm for innovations that may support earlier detection and improved outcomes across other cancer types.

One attendee expressed, “you get an answer there and then… that would be just the most amazing thing,” highlighting the value placed on immediate clarity and reduced waiting times in the diagnostic process.

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?

Attendees engaged in a detailed discussion on whether it is practical to target GP clinics for the use of this tool, rather than specialist clinics.

Key insights included:

Strong support for GP based delivery due to accessibility - Attendees consistently supported the use of the tool in GP settings, noting that GPs are far more accessible than specialists, particularly in regional and rural areas. This was seen as critical for improving early diagnosis and reducing delays in care.

Opportunity to support earlier intervention and reduce pressure on specialist services - Attendees highlighted that enabling GPs to diagnose and manage earlier stage lesions could reduce the need for specialist involvement in straightforward cases. This would allow specialist services to focus on more complex or advanced conditions, improving overall system efficiency and access for those with higher clinical need.

Potential to strengthen trust within existing care relationships - Where there is an established relationship with a trusted GP, attendees felt that access to improved diagnostic tools would enhance confidence in care. However, this was balanced against concerns about variability in GP capability, reinforcing the importance of ensuring appropriate training and competency in use of the tool.

Expanding the workforce able to use the tool - Attendees suggested that use of the tool could extend beyond GPs to include practice nurses, increasing flexibility and access within primary care settings. This was seen as particularly valuable in high demand or under resourced settings, provided the tool is easy to use and supported by appropriate training.

Integration with alternative and community based delivery models - Attendees proposed a range of additional settings where the tool could be deployed to improve reach and accessibility. These included mobile services similar to breast screening programs, community outreach models, pharmacies, Cancer Council services, and existing community health initiatives. These approaches were seen as particularly valuable in rural and remote areas.

Practical considerations of cost and appointment structures - Some attendees noted that GP based skin checks can require longer or multiple appointments, increasing both cost and time burden. Consideration of how the tool integrates into standard consultation models will be important to ensure it does not inadvertently increase barriers to access.

QUESTION 3 (CONT)

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?

Potential to improve referral pathways and triage - Attendees highlighted that if the tool could provide more detailed diagnostic information, including identification of cancer type and severity, this could strengthen referral processes. Providing this information upfront may support more effective triaging by specialists and prioritisation based on urgency.

Addressing system level barriers to specialist access - Attendees reinforced that access to specialist care is often limited by referral requirements, cost, and availability. Positioning the tool within GP settings was seen as a way to reduce these barriers and enable more timely escalation of care when needed.

One attendee expressed, “it’s really hard to access specialist clinics,” highlighting the importance of accessibility in shaping where this technology should be deployed.

ADDITIONAL REFLECTIONS

Attendees were invited to share any additional reflections for the research team.
Key insights included:

Accessibility as a central priority - Attendees strongly emphasised that improving access to timely and affordable care must remain a core focus. Significant challenges were described in accessing GP services in regional areas, including long waitlists, limited availability of bulk billing, and barriers to being accepted as a patient within local clinics.

Health system inequity in regional settings - Attendees highlighted that access to care in regional areas is often dependent on financial capacity, availability, and persistence. The need to pay out of pocket for standard GP appointments and ongoing care was described as a significant burden, contributing to inequitable access to diagnosis and treatment.

Importance of outreach and alternative delivery models - Attendees identified mobile and outreach services, including travelling nurses and community based clinics, as having strong potential to improve access in rural and remote communities. These models were described as potentially life changing in reducing delays and reaching populations less likely to attend traditional clinical settings.

Need for self advocacy within the current system - Attendees reflected that individuals often need to actively advocate for their own care in order to access appropriate diagnosis and treatment. This included pushing for referrals, follow up, and further investigation, particularly in regional settings where services are constrained.

Impact of access barriers on health outcomes - Attendees highlighted that delays, cost, and system barriers can directly influence outcomes, with contrasting experiences demonstrating how early diagnosis and intervention can differ significantly between individuals.

Importance of inclusive involvement opportunities - Attendees noted that opportunities for involvement are often metro based and not always accessible to those living in regional areas. Expanding access to online involvement opportunities was seen as important to ensure regional voices are represented in research.

Interest in research progression and real world impact - Attendees expressed strong interest in understanding the timeline for development and implementation of the technology, and a desire to remain involved as the research progresses. There was clear support for the research and recognition of its potential to improve outcomes, particularly in regional communities.

CONNECTING INSIGHTS ACROSS METRO AND RURAL COMMUNITY CONVERSATIONS

This Micro Community Conversation builds on the earlier metro-based Conversation held in 2025, providing an opportunity to explore how experiences and priorities compare across different settings.

Despite differences in geography and context, there was a strong alignment in the core challenges described by attendees. Across both Conversations, attendees consistently highlighted delays in diagnosis, misdiagnosis at the point of first contact, and the burden of repeated procedures. These shared experiences reinforce that challenges within the current diagnostic pathway are not isolated to one setting, but reflect broader system issues.

At the same time, the rural Conversation provided additional depth and clarity around how these challenges are amplified in regional and remote contexts. Issues relating to access, cost, workforce availability, and the need for self-advocacy were more pronounced, highlighting the inequities experienced outside metropolitan areas. Importantly, both groups expressed strong support for a non-invasive, point-of-care diagnostic tool, particularly one that could be deployed in GP and community-based settings to enable earlier diagnosis and reduce reliance on specialist pathways. Together, these findings demonstrate both consistency in the need for improved diagnostic approaches and a clear opportunity for this research to deliver meaningful impact, particularly in improving access and equity across diverse settings.

WHAT'S NEXT?

The insights from both the metro and rural Micro Community Conversations will directly inform the ongoing development of the non-invasive skin cancer probe, ensuring it is responsive to real-world needs and challenges. As the research progresses, there will be continued opportunities for consumer involvement to guide design, usability, and implementation considerations, particularly in relation to accessibility, trust, and integration into primary care settings. This ongoing involvement will support the translation of the technology into a practical, equitable solution that improves early diagnosis and outcomes across diverse communities.

WANT TO KNOW MORE?

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