



Consumer and Community
Involvement Program



WAHTN

Western Australian Health Translation Network



Fiona Wood Foundation

BURNS RESEARCH

COMMUNITY CONVERSATION REPORT



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AUGUST
2023

MU Murdoch
University



Government of Western Australia
South Metropolitan Health Service

FIONA
STANLEY
hospital

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ACKNOWLEDGEMENTS

Acknowledgement of Country

The Western Australian Health Translation Network (WAHTN) and Consumer and Community Involvement Program (CCIProgram) acknowledges the Aboriginal people of the many traditional lands and language groups of 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.

Other Acknowledgements

We would like to express our sincerest gratitude to all the consumers and community members who attended the Community Conversation; your time, energy and contributions are all greatly appreciated.

Lastly, we would like to acknowledge members of both the WAHTN team and members of the Fiona Wood Foundation and Murdoch University for their diligent work in planning, promoting, and successfully facilitating the event.



BACKGROUND

The Fiona Wood Foundation research team actively partnered with the Consumer and Community Involvement Program to facilitate a Community Conversation to bring together burn survivors from across WA to discuss views on burns-related research at the FSH State Burns Unit. The information obtained during the event will be used to inform research directions and priorities and support future research and grant applications focusing on improving our understanding of burn injury and the interactions with the skin and all body systems and the development of new technologies and treatment to improve clinical care and improve outcomes.

THE CONSUMER AND COMMUNITY INVOLVEMENT PROGRAM

The Consumer and Community Involvement Program (CCIProgram) is an enabling platform of the Western Australian Health Translation Network (WAHTN). The CCIProgram actively supports partner universities, health and medical research institutes, health service providers and non-Government organisations to bring together consumers and people with lived experience and connect them with health and medical researchers. The success of the CCIProgram comes through building and maintaining strong relationships with WAHTN and Partner Organisations.

Consumers and community members are an integral part of the research process, allowing for greater transparency, openness and accountability leading to research which is more relevant and impactful to the community. Our aim is for consumer and community involvement to be standard practice in all health research in Western Australia. As such, our services, resources and training programs have been developed to support consumers and community members being involved at all stages of the research cycle.

CCIProgram Team:

Deb Langridge, Head
Ingrid Laing, CCI Coordinator
Kerry Mace, CCI Coordinator
Jillian Northwood, CCI Coordinator
Kat Stewart, CCI Coordinator
Briony Abraham, Event Officer



THE FIONA WOOD FOUNDATION

Led by plastic and reconstructive surgeon and burns specialist Professor Fiona Wood AM, the Fiona Wood Foundation is a non-for-profit organisation facilitating the translation of knowledge and ground-breaking research into pioneering criteria and treatment for burn injury survivors. At its core, the Foundation aims to improve the outcomes and quality of life for all individuals affected by a burn injury. The Foundation exist for both current and future patients and recognises that every intervention from the point of injury influences the scars in both mind and body. With the support of partners (including Murdoch University and Fiona Stanley Hospital), and our very generous community, the Foundation brings together the best scientists, researchers and clinicians to meet its objectives to: improve understanding of burn injury and the interactions with the skin and all body systems; develop new technologies and treatment to improve clinical care; improve mental health outcomes; and educate the community.

Some of our current research project include:

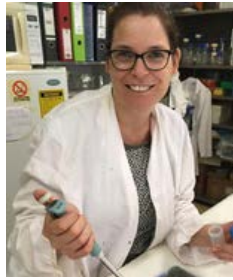
1. The BioBank Project. This project aims to understand how biological responses to burn injury are related to recovery, we hope this understanding may help us to personalise treatment for burn injury survivors to improve overall health and wellbeing.
2. The Neuroplasticity Project. This project is aimed at understanding the changes that occur in the communication between the brain and body following a burn injury. The brain has a lot to do with the recovery and rehabilitation process because it controls how we move our body and what we feel when something touches our skin. If we can understand the disruptions that occur in communication between the brain and body after a burn injury, then we might be able to help regulate this communication and boost or speed up the recovery process.
3. The Scar Pill Project. Scars are a natural and, sadly, a common occurrence after a burn injury. Scar appearance can impact sensation and movement, which can lead to difficulties with simple daily activities. The Foundation is testing different approaches to reduce the severity and improve the appearance of scars after a burn injury at different stages of the healing process. This Scar Pill Project targets the “remodelling stage” – this is the stage immediately after the burn has healed but not yet matured. We hope to improve the appearance of scars as well as improve the flexibility, movement, and sensation of scars.
4. The Burns-related Pain Project. Both short-term and long-term pain can cause challenges to recovery after a burn injury. Pain can greatly impact day-to-day functioning, burn management and the healing of the mind and body. This study aims to better understand the mechanisms of pain following a burn injury, so that we can develop more direct and efficient ways of managing pain in the short and long term.



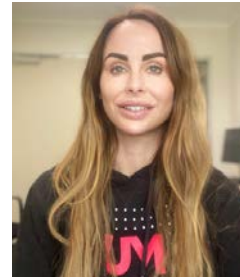
THE FIONA WOOD FOUNDATION RESEARCH TEAM



Dr Grant Rowe
Post-doctoral Researcher



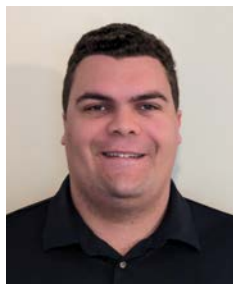
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Research Co-ordinator



Mr Tyler Osbourne
PhD Research Student



Ms Alecia Wood
Honours Research Student

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Prof Fiona Wood,
Plastic and
Reconstructive
Surgeon, Director of
State Burns Services
& Founder of the
Fiona Wood
Foundation.



A/Prof Mark Fear
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**A/Prof Ann-Maree
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and Cognition Research
Group.



A/Prof Dale Edgar
Associate Professor at
the University of Notre
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and FWF Research Lead
for Rehabilitation.

WHAT IS A COMMUNITY CONVERSATION?

A Community Conversation is an event using an abridged version of the Word Café Method[1] and allows for the facilitation of informal, open conversations around a specific topic of importance. This method allows researchers to informally obtain a range of communal ideas from a group of people with lived experience around a particular topic specified prior to the event [2,3]. Additionally, a Community Conversation provides an opportunity for attendees to reflect upon their own relevant experiences and contribute in meaningful discussions within a safe and comfortable space.



[1] Brown, J., & Isaacs, D. (2005). *The World Cafe : Shaping our futures through conversations that matter*. Barrett-Koehler

[2] Chieh-Ling Yang, Delphine Labbé, Brodie M. Sakakibara, Janneke Vissers & Marie-Louise Bird (2022) World Café- a community conversation: a Canadian perspective on stroke survivors needs for community integration, *Topics in Stroke Rehabilitation*, 29:5, 392-400.

[3] Carter, E. W., Schutz, M. A., Gajjar, S. A., Maves, E. A., Bumble, J. L., & McMillan, E. D. (2021). Using Community Conversations to Inform Transition Education in Rural Communities. *The Journal of Special Education*, 55(3), 131-142.

ABOUT THE COMMUNITY CONVERSATION

Approach

The Research Team recognises the unique perspective consumers and people with lived experience can contribute regarding their personal health background. In partnership with the CCIP Program, a Community Conversation was planned to gather and collect thoughts and attitudes from burns survivors.

The aim of this Community Conversation was to promote discussion surrounding burn-related research and how it can help recovery after a burn injury. A total of 24 community members with lived experience attended the event along with 6 members of the Consumer and Community Involvement Program and 8 researchers from the Fiona Wood Foundation and Murdoch University.

The conversation took place in the form of 4 individual groups discussing the same questions, with a WAHTN facilitator and a Fiona Wood Foundation scribe at each table, participants had 20 minutes to discuss each of the 3 questions .



Promotion

The Fiona Wood Foundation worked closely with the CCIProgram team to contact past patients and share promotional communications across multiple channels.

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



Volunteers Needed

Murdoch University and the Fiona Wood Foundation are seeking **individuals** who have sustained a previous **burn injury** to **share their experiences**.

WHAT WILL BE INVOLVED?

You will be asked to attend a 2 hour "community conversation" event at Murdoch University.

At the event, we will ask you questions about:

1. Your experience with burn injury;
2. Your views on research participation;
3. What mattered to you most during recovery.

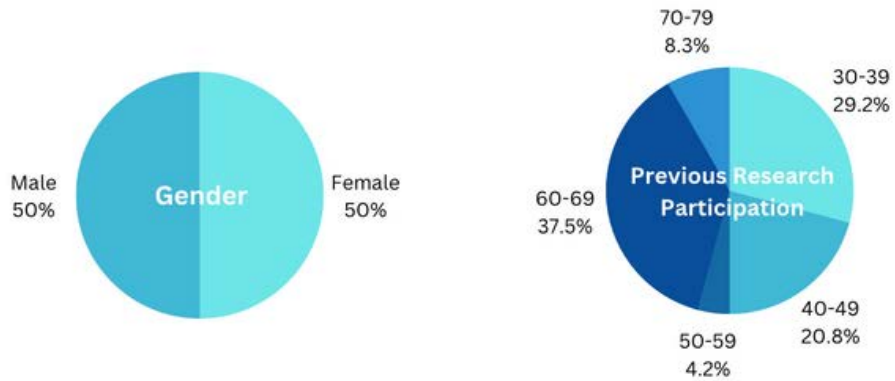
Parking, food, and drink will be provided.

For more information please ☎ 08 6152 0318 or scan the QR code:

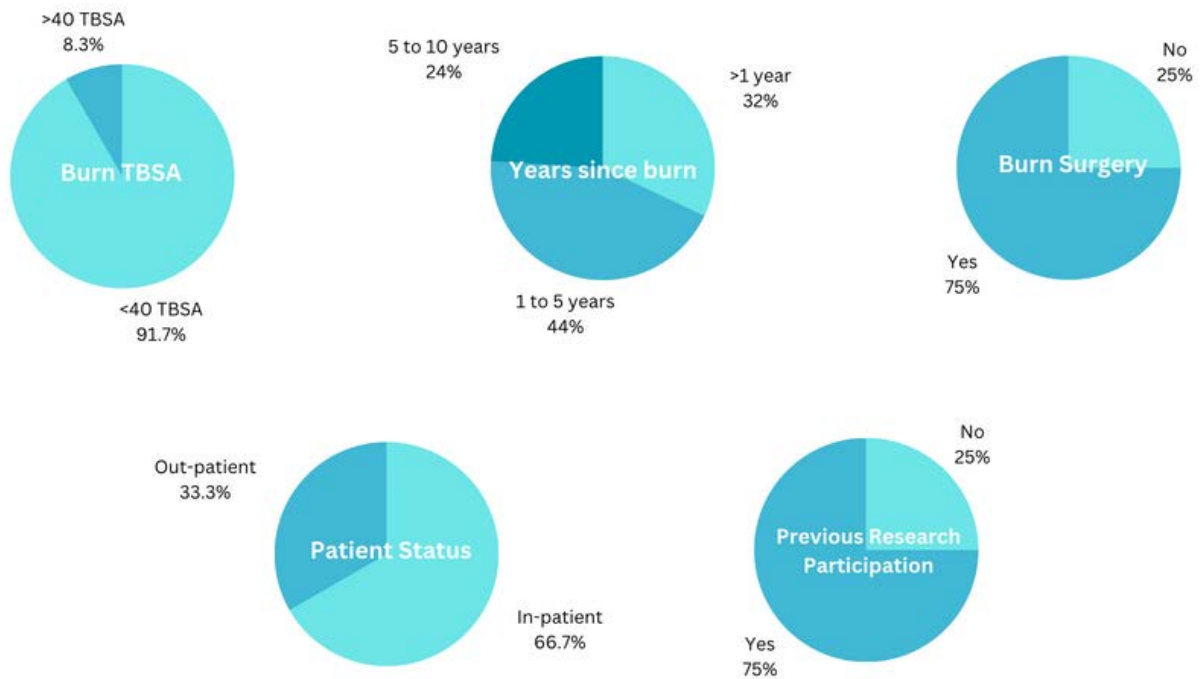


ATTENDEES

Demographic Information



Participant Burn Characteristics



EVENT PROCEEDINGS

5.30 pm	Registration, honorarium, & refreshments	All
6.00pm	Welcome <ul style="list-style-type: none"> • Acknowledgement of Country • Welcome to the workshop • Introductions 	Jillian Northwood
6.10pm	Presentation & questions	Fiona Wood & Ann-Maree Vallenge
6.20pm	Process of the evening	Jillian Northwood
6.30pm	Question 1: What aspects of recovery from burn injury were most important to you?	All
6.50pm	Question 2: What are some barriers that would prevent you from taking part in or completing burns-related research?	All
7.10pm	Question 3: What are some factors that would motivate you to take part in burns-related research?	All
7.30pm	Table facilitator feedback	Table facilitators
7.45pm	Next steps and questions	Jillian & Ann-Maree
7.50pm	Evaluation	
8.00pm	Close	

Attendees were split between 4 tables. Each table had a facilitator from the CCIP program to help guide the discussion and a scribe from the Fiona Wood Foundation Research Team to collect all attendee feedback.

Facilitators posed 3 questions in total to the group, attendees had approximately 20 minutes to discuss each question with table facilitators. The comments, feedback and suggestions were all captured by each scribe and are presented in the following pages of this report.

COMMUNITY CONVERSATION FINDINGS

Attendee Insights

QUESTION 1: What aspects of recovery from your injury were most important to you?

Participants described their experiences recovering from a burn injury and discussed some of the challenges they faced. The most common challenges raised included physical challenges, psychological challenges, and lack of information.

The physical challenges included scar and injury appearance, pain, functionality and mobility changes, and the effect of these factors on recovery and ability to return to work and caring roles. The psychological challenges included traumatic responses to the injury and rehabilitation, adjusting to aspects of life following the injury, and the burden of the injury on family members.

Burn survivors mentioned the value of information and education following their injury, and many shared a desire for additional information and support during the recovery process, particularly when discharged from hospital. Many burn survivors felt supported by the multidisciplinary approach of the burns services and appreciated greatly the impact and work Professor Fiona Wood has put into bettering healthcare outcomes for burns patients.

A closer look at the most common themes that emerged from responses to this question:

Physical challenges:

- *Burn / Scar appearance. "Was I going to look the same". With regards to wearing a bathing suit: "I can't, I'm in compression garments".*
- *Pain. "All of us have been through horrible pain". "Childbirth was a breeze". Burn survivors were uncertain about when the pain would go away and the duration of medication use.*
- *Functionality / mobility. Injured area and skin caused practical challenges: "You are incapacitated, immobile and need to elevate injury for a long time, cannot do home care"; "Cannot get dressed"; "Need to return to work"; "Important that I could pick up my grandchildren". Burn survivors mentioned the physical challenges causing lack of activity during recovery, but also overdoing rehabilitation causing additional issues/hospitalisation.*

COMMUNITY CONVERSATION FINDINGS

Attendee Insights

QUESTION 1 cont.

Psychological challenges:

- *Vulnerability.* Burn survivors mentioned feeling vulnerable when people watch them struggle with daily tasks, such as getting dressed.
- *Triggers.* Burn survivors mentioned being triggered in situations following the burn injury that wouldn't have caused an issue before the burn injury, such as an extra hot coffee order, proximity to gas appliances, and looking for escape options.
- *Adjustment.* Burn survivors mentioned the psychological adjustment to "new life", "new normal", "some sort of normal life", "be as normal as possible", "Is life ever going to be normal again", "want to go back to normalcy"; "better off alive than having died from the burn". Some burn survivors struggled with the ebb and flow of recovery. Some burn survivors mentioned feeling guilty that the injury was their fault, while others accepted that their injury was an accident. Some burn survivors mentioned feeling isolated, angry, stressed, and anxious following the burn injury, related in part to the uncertainty of the situation.
- *Family / caregiving.* Burn survivors mentioned that they didn't want family affected or burdened by their injury and there was no support for the family despite their suffering: "the family suffer probably as much as you do as a patient, but they don't have the drugs to make you forget everything".

Information:

- *Staff and hospital.* Some burn survivors mentioned they received helpful explanations from staff, viewed helpful posters at Fiona Stanley Hospital, and a lot of resources were available. Some burn survivors mentioned that explanations were helpful but could have been improved and increased.
- *Recovery pathways.* Burn survivors wanted information about pathways to return to normal life and to see others who have been through something similar, to see a way forward.
- *Treatment.* Burns survivors wanted more information to understand what is happening and how does it relate to recovery: "to understand my body"; "knowing what this dressing is doing and how to change it properly and what not do". Burn survivors wanted more education about pain management, including with regards to medication misuse.
- *Education.* Some burn survivors reported having no burn first aid education before their burn injury.

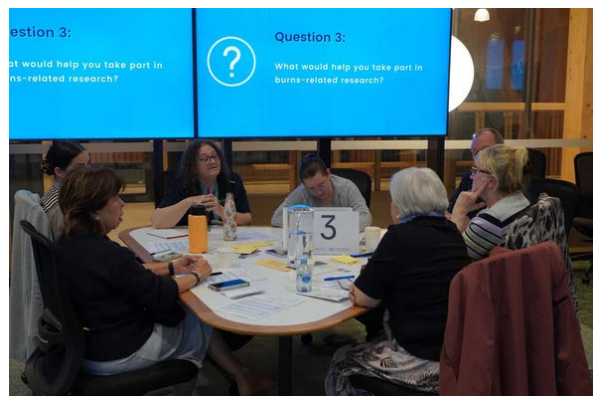
COMMUNITY CONVERSATION FINDINGS

Attendee Insights

QUESTION 1 cont.

Support:

- *Discharge.* Some burn survivors got support at home from Silver Chain and other services and found the virtual appointments positive, however some burn survivors lacked support with home tasks and childcare, experienced financial stress, and felt “*thrust into the world*”.
- *Group support.* Burn survivors mentioned a burn injury survivor group would be helpful to share experience with other patients: “*Inspired by your fellow patients. We’re in it together*”; “*Motivation from past patients going, ‘Oh, yes, I probably can get through this. He did it so I could do it’*”.
- *Treatment.* Burn survivors reported excellent multidisciplinary support, feeling “*wrapped around*” by healthcare, and that things have changed for the better over the last 10 years.



COMMUNITY CONVERSATION FINDINGS

Attendee Insights

QUESTION 2: What are some barriers that would prevent you from taking part in burns research?

There was a mix of research experience in the burn survivors at the Community Conversation: some had taken part in burns research, some had been contacted about burns research but not taken part, and some had not been contacted about burns research. Participants described their experiences with burns research and discussed barriers and concerns regarding burns research.

Time was described as the main barrier. There were also practical barriers discussed, such as finding childcare, location of the research, flexibility with work commitments. Psychological barriers were discussed, as well as perceived value both in the context of patient knowing the value of their participation and in the context of the researcher showing that they value the burn survivor. Understanding the specific research project and research more broadly with regards to how it impacts patient care, and the communication of the research were identified as barriers. In discussing the barriers, there was a consensus: *"Make it as easy as possible for us to participate and we will say yes!"*

A closer look at the most common themes that emerged from responses to this question:

Time:

- *"Time is the biggest factor"; "The time sacrifice needed for research can make it difficult to commit, even if we really want to."*

Practical barriers:

- *Caring responsibilities.* Family commitments and childcare barriers: *"Family care support from researchers - maybe ability to leave children somewhere or with someone at research centre to help with this."*
- *Work commitments.* Difficult to participate without workplace flexibility or a supportive work environment. Option to participate during lunch break would be helpful.
- *Location.* Single location for participation and coming to that location for a short session is a barrier. Linking with other services to offer more locations or more flexibility.
- *Accessibility.* Make accessibility to the research locations and the research team as easy as possible. Provide snacks during sessions.

COMMUNITY CONVERSATION FINDINGS

Attendee Insights

QUESTION 2 cont.

Physical barriers:

- Attend research session could be difficult depending on when during the recovery process the research is meant to take place. If for example it is in the early stages, *"Couldn't do anything - said to have it elevated 23 hours a day."*

Psychological barriers:

- *Reliving the experience.* Fear of reliving the experience. Burn survivors spoke about risk vs reward of research and what they will get out of it – will it bring back memories / make them relive what they went through.
- *Poor mental state.* *"I felt like an idiot for getting burned"*. Low motivation to participate in research.

Value:

- *Value as a participant.* Burn severity associated with helpfulness: *"If my burn is not severe, I don't think I'm suitable"; "Hearing other stories made me feel like a fraud if my injury wasn't as severe"*. Burns survivors assumed they didn't have knowledge that could be helpful to research: *"I thought I didn't have anything to add."*
- *Valued by researchers.* Make clear that the research team understands the value of the burn survivors time, experience, and expertise.

Understanding and communication:

- *Why.* Not understanding the importance of the research relative to recovery. Quick and clear communication is important, showing the genuine intent of the researcher. Important to show who researchers are helping, what researchers are trying to achieve, and how this will impact treatment and management of burns.
- *Involvement.* Need to make clear and ensure the burn survivor comprehends what the study or project looks like (beginning to end) and what is required of them. Not understanding exactly what's involved is a barrier: *"what are you asking of me?"*. The importance of burn survivors' involvement needs to be made clear – challenges in doing research and the implications if there are not enough participants.
- *Impact.* Make clear how research has changed over time and how it has gone on to impact patient care, for example the story of Fiona's Spray On-Skin. Some burn survivors want to engage in personalised research that they will benefit from.
- *Research progress.* Burn survivors want more follow-up and to be updated on research progress.

COMMUNITY CONVERSATION FINDINGS

Attendee Insights

QUESTION 3: What are some factors that would motivate you to take part in burns-related research?

Burn survivors discussed the importance of clear communication for deciding whether to participate in research, highlighting the need to understand the big picture regarding the research. Burn survivors described some motivators for research participation, such as being inspired by Fiona Wood, wanting to give back and improve treatment for future burn survivors, and feeling valued for their contribution to research. Attendees stated that a personalised approach to research such as receiving individual results and progress reports, would motivate them. Further supports that would make one more likely to participate in research were identified, including childcare support, travel and parking, and flexibility in participation.

A closer look at the most common themes that emerged from responses to this question:

Understanding and communication

- *Why. Understanding research and the bigger picture: "Understanding importance of what you're doing as a research participant"; "I want the bigger picture first. The email I got didn't explain the bigger picture, the greater good."*
- *Outcomes. Communicating the outcomes of the research in a timely manner: "Patients want to know what has been achieved from the work they were involved in; this will improve the chances that they stay involved with burns research."*
- *Research awareness. "Having a dedicated research noticeboard in the waiting room to highlight its importance."*

Fiona Wood

- *"A trusted, inspiring person whose dedication precedes her." "You have Fiona Wood as the brand equity."*

Giving back

- *The opportunity to give back for the excellent care received & turn my negative experience into something good: "Happy to embrace the process of research in both the acute and chronic phase of the recovery if it will improve future experiences."; "I would jump big hurdles to show my gratitude for what the burns service did for me in my time of need."; "Being able to show our gratitude for the medical care we received is incredibly rewarding."*

COMMUNITY CONVERSATION FINDINGS

Attendee Insights

QUESTION 3 cont.

Feeling valued

- *Relationship with research team.* Building a rapport with the research team and hearing the gratitude from the research team for their participation. Keep research and contact personalised to “feel valued”.
- *Acknowledgement of participation.* Not necessarily money (although it is appreciated); “could be chocolate milk and sausage roll”; “a badge that says I participated”.

Individual benefit

- *Individual outcomes.* Burn survivors are interested in the individual results from the tests that they completed: information about personal progress; feedback on individual results, even after the research has concluded; direct benefit from research, what it can mean for them.
- *Recovery.* Possible “promise of going back to normal” as a result of research. Motivation to improve recovery.

Support

- *Flexibility.* Design research for inpatient settings or portable research – “come to my house” to do research / collect samples – would help in retaining participation in research.
- *Practical support.* Help with travel to research centre; parking vouchers; family caregiver responsibilities; remuneration; snacks.
- *Peer involvement.* “More research options involving more people. I’d be keen for that. Like a group setting.”



EVENT SUMMARY

Evaluation and feedback from attendees were collected through the CCIProgram following the closing of the Community Conversation. The consensus from all who attended was that the Community Conversation was extremely informative, interactive, and engaging. Attendees were enthusiastic around their involvement with this particular event and commented that they felt their contributions were valued and appreciated. Overall, the event was extremely successful and will allow for the research team to provide informed consumer and community member feedback for further grant opportunities and research priorities.



WHAT'S NEXT FOR BURNS RESEARCH?

The researchers found the information that came out of the Community Conversation very informative, and it will be using details and views provided in the structure and formation of new burns related research studies. For all of our studies, we will pay attention to communication of the importance of the research for burn survivors and exactly what is required of burn survivors, as well as timely communication of outcomes. We will also consider the practical aspects of our research, and how we can be more accommodating to the needs of burn survivors, particularly soon after injury.

We will use the outcomes of the Community Conversation to develop new research projects that address key challenges faced by burn survivors. For example, we will design studies aimed at understanding and treating pain following burn injury.

Finally, we would like to continue to learn from those with lived experience of burn injury, and will develop an online survey aimed at engaging the wider burns community to better understand views on burns related research and barriers and motivators for participation.

FUTURE OPPORUNITIES WITH THE FOUNDATION



We are currently seeking one or two “Research Buddies,” these are individuals who have a lived experience of a burn injury. Research Buddies will be asked to provide feedback on the development, implementation, and completion of future burns-related research. If you are interested in this opportunity, please contact: Bronwyn Rowe at Bronwyn.Rowe@murdoch.edu.au.

We also post all our current research on the Fiona Wood Foundation website: <https://www.fionawoodfoundation.org.au/research-hub/participate-in-current-research-studies>.

Join our burns family:



For any further inquiries, to donate, or to connect further with the Foundation, please reach out to our wonderful Executive Manager.

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Diane Lim,
Fundraising, Relationships and Executive Management

Find us on:



We would like to thank the community members who attended the Community Conversation for their participation: your time and dedication is deeply appreciated.



Fiona Wood Foundation

WANT TO KNOW MORE?

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