



Participant Information Sheet & Consent Form

Title	Western Australian Patient Self-Reported Impact on Quality of Life After Burn Injury: Part 1 - Ultralong Follow-up After Burn (ULFAB)
Short Title	Life After Burn: ULFAB Part 1
Coordinating Principal Investigator	Assoc Prof. Dale Edgar, Research Fellow, Institute for Health Research, The University of Notre Dame Australia and State Adult Burn Unit, Fiona Stanley Hospital, WA.
Principal Investigators	W. Prof Fiona Wood, Dr Helen Douglas, Prof Suzanne Rea, Dr Ed Raby, Dr Lisa Martin, Dr Inge Spronk
Locations of Research Activities	Fiona Stanley Hospital, Murdoch, WA; University of Western Australia, Crawley, WA.

Part 1: What does participation involve?

Introduction

The *Life After Burn* study is a Western Australian research project aimed at understanding how burn injuries may impact people's lives in the years following treatment. It is the first local study to explore long-term quality of life through the experiences of people who received burn care in WA since 1993. By participating in a one-time survey, participants can help researchers build a clearer picture of whether burn injury has had an impact on their lives, which may inform future care, services, and research.

By taking part, you may contribute to research that aims to understand:

- Find out how burn injuries may affect people's daily life over time - such as their ability to walk around, care for themselves, work, or do activities they enjoy
- Look at what factors might be linked to these outcomes (such as how severe the burn was, what treatment was needed, pain levels, or feelings of anxiety)
- Compare how people with burn injuries in WA are doing to the general Australian population

This sheet gives you information about the research project and what it means if you decide to take part. Participation is entirely your choice. Deciding not to take part will not affect any



care or services you receive now or in the future. If you choose to participate, you will be asked to complete a one-time, online survey.

What is the purpose of this research?

A burn injury can affect more than just the skin. While early treatment often focuses on wound healing and physical recovery, some individuals may experience ongoing impacts that affect movement, emotional well-being, or their day-to-day life. In Western Australia (WA), specialist burn care is typically provided for up to two years; however, very little is known about how people are doing five, ten, or even twenty years later.

This research project recognises that recovery looks different for everyone. By sharing your lived experience, you are contributing to important research. Your input helps researchers understand what life is like after a burn injury and may help ensure that future care and research better reflect the needs, values and priorities of the people they are intended to support.

What will I be asked to do?

If you decide to take part, you will complete a short, confidential online survey. It should take about 10-15 minutes and involves:

- **Questions about you and your past burn injury** - such as when it happened and what treatment you received
- **Five questions about your physical and emotional health today** - covering mobility, self-care, usual activities, pain, and emotional wellbeing (using a scale from 1 "no problems" to 5 "extreme problems")
- **One final question asking you to rate your overall health** on a scale from 0 (worst imaginable) to 100 (best imaginable)

The survey is hosted on REDCap, a secure research platform used by WA Health. Your responses will be stored securely for 7 years as per WA Health requirements, then safely deleted. You can access it using the **QR code** or this secure link: **<REDCap link>**.

At the end of the survey, you will be asked whether you would like to:

- Receive a summary of the study findings when available
- Allow us to check your answers against your medical records (to verify burn injury details)
- If you want to stay connected with the Fiona Wood Foundation or members of the research team.

If you agree to any of these, you will be asked to provide your contact details.

Is participation voluntary?



Yes. Taking part is completely voluntary. You can skip questions or stop the survey at any time before submitting it. You do not need to explain your decision, and it will not affect your access to care or services.

If you choose to participate, you will be asked to sign the consent section of this form. By signing, you confirm that you:

- Understand what you have read
- Agree to take part in the Life After Burn study
- Consent to the use of your personal and health information, as described in this form

You will also receive a copy of this form for your records.

What are the possible benefits?

This research may not benefit you directly, but your participation may help improve understanding of life after burn injury in WA. Your responses could inform better care, services, and future research for others.

Are there any risks?

We do not expect that taking part in this research project will cause you harm. However, some of the questions may bring up difficult memories or feelings related to your injury or recovery. If this happens, you are welcome to skip any question or stop the survey.

If you feel upset or need someone to talk to, there are people and services who can help:

- Lifeline – Call 13 11 14 (available 24/7)
- Beyond Blue – Call 1300 22 4636 or visit beyondblue.org.au/get-support
- 13YARN – 13 92 76 (available 24/7)
- Your GP or local Emergency Department

The survey is not a medical or psychological assessment. However, if your answers suggest emotional distress, a message will appear on the screen to gently encourage you to seek support. A complete list of support services is available on the Fiona Wood Foundation website <https://www.fionawoodfoundation.org.au/patient-community-hub/patient-support-resources/post-injury-support-services>

If you feel suicidal or in danger of harming yourself, please call Lifeline immediately on 13 11 14, or attend your local Emergency Department.

Can I stop taking part once I start?

Yes. You can withdraw at any time before submitting the survey. If you change your mind after consenting, you may email the research team or complete a Withdrawal Form. Once



your responses are submitted, they are stored securely, without your name or any identifying details, and cannot be withdrawn. However, if you withdraw before submission, no data will be saved. Participation or withdrawal will not affect your future access to care or services.

Could the research project be stopped unexpectedly?

In rare cases, the research project may need to be paused or terminated due to changes in funding, staffing, or technical systems.

What will happen to my information?

Your responses will be stored securely in REDCap, a secure online survey platform hosted on a WA Health server. You will not be identified in the survey unless you choose to provide your email address.

Each survey response is assigned a unique ID number. This allows the research team to check your answers against medical records if needed. Any identifying details (like your name) will be kept in a separate, secure file and only accessed by senior members of the research team if needed for example, to fix an error or verify data.

All information is stored securely according to WA Health policies and national ethical guidelines. Any paper consent forms will be scanned and securely stored in digital form, then destroyed. All digital data will be kept on a secure WA Health server for at least seven years, and then safely deleted.

If you agree to future contact, your email will be stored separately from your survey responses and used only to contact you about future burn-related research.

The results of the study may be published in journals or presented at conferences, but your identity will never be disclosed. Anonymous data may also be used in future research with approval from a WA Health ethics committee, but you will not be identifiable in any future projects.

How will I find out about the results?

If you choose to provide your email address at the end of the survey, the Fiona Wood Foundation will contact you with a summary of the study's findings. You can expect to receive this update in late 2027.

Results will also be shared publicly in the following ways:

- On the **Fiona Wood Foundation website**: www.fionawoodfoundation.org.au
- Through publication in open-access, peer-reviewed journals (e.g. *Burns*, *European Burn Journal*)

All results will be presented as grouped data only. No one will be personally identified in any report or publication.



Who is organising and funding the research?

This study is led by Associate Professor Dale Edgar (Institute for Health Research, The University of Notre Dame Australia; State Adult Burn Unit, Fiona Stanley Hospital). The Fiona Wood Foundation is coordinating the public-facing campaign and has provided philanthropic funding to support the project.

Who can I contact if I have questions about the project?

If you have any questions or concerns about the *Life After Burn* study or if you have any questions about your past, or possible future treatment for your burn injury and scarring, you are welcome to contact the Coordinating Principal Investigator:

Associate Professor Dale Edgar

Institute for Health Research, The University of Notre Dame Australia
State Adult Burn Unit, Fiona Stanley Hospital

Phone: 0413 070 384

Email: dale.edgar@health.wa.gov.au

What if I have a complaint?

The Central WA Health Human Research Ethics Committee has approved this research project. If you have a complaint about how the study is being conducted or are concerned about your rights as a participant, please contact:

Central Office of Research Ethics (CORE)

Phone: (08) 9222 4214

Email: HREC@health.wa.gov.au

Please quote the project number: **RGS00007746** when you contact them.

How do I sign up to participate?

If you are completing a paper version of this form, please sign the consent section on the next page. You may return a scanned copy by email to: dale.edgar@health.wa.gov.au

If you are completing a digital version, you can sign the consent form on screen. A copy of this information and your signed consent will be emailed to you automatically.

Thank you for considering taking part in this research.



Part 2: Consent Form Quality of Life Impact After Burn Injury

If you have any questions before signing, please don't hesitate to contact the Chief Principal Investigator, Associate Professor Dale Edgar, at dale.edgar@health.wa.gov.au or phone 0413 070 384.

Please read the statements below and tick the boxes that apply to you.

REQUIRED CONSENT (must tick all boxes below to participate):

- I have read the Participant Information Sheet and understand what participation involves.
- I have had the opportunity to ask questions and have them answered.
- I understand I will be asked questions about myself, my burn injury, and my current health.
- I know I can skip any question or stop the survey at any time before submitting it.
- I understand that taking part is voluntary, and I can withdraw at any time before survey submission without any impact on my care or services.
- I understand that my information will remain confidential and stored securely for 7 years in line with WA Health and ethics guidelines.
- I agree that anonymous data collected during the study may be used in research publications or presentations.
- I understand that my identity will never be disclosed in any reports or publications.
- I understand that this signed form will be stored securely and retained according to WA Health research guidelines.

OPTIONAL CONSENT (tick only those that apply to you):

- I agree to let researchers match my survey answers with details in my medical records for data validation purposes.
- I would like to receive a summary of the study findings when available (contact details required below).
- I consent to receiving future communications from the Fiona Wood Foundation or the Burn Service of Western Australia about research opportunities (contact details required below).
- I understand and agree that anonymous data from this study may be used in future research projects if approved by a WA Health Human Research Ethics Committee.

CONTACT DETAILS (complete only if you ticked the boxes above requiring contact):

Email:

This project was granted ethical approval by WA Health Central Human Research Ethics Committee (HREC). If you have any concerns about the conduct of the project or your rights as a participant, please call the Central Office of Research Ethics on 08 9222 4214 or email: HREC@health.wa.gov.au and quote the project number (RGS0000007746).

Name of Participant (please print)		
Signature of Participant (or indicate verbal consent)		Date:



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I confirm that the participant has indicated they have read the Information Sheet for this research project and all questions have been addressed via email or in discussion with the Chief Investigator.

Signature of Researcher		Date:
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Withdrawal from Participation

Study Title: Quality of Life Impact After Burn Injury

Coordinating Principal Investigator: Assoc Prof Dale Edgar

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that withdrawal from the study will not affect my routine or future treatment, my relationship with those from the Burn Service of Western Australia and allied hospitals.

Please choose one of the following:

- I consent for the data collected from me to date to be kept and included in the study analyses.
- I wish for my recorded data to be removed from the study analyses.

Name of Participant (please print)		
Signature of Participant (or indicate verbal consent)		Date:

Declaration by Senior Researcher[†]

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Signature of Researcher		Date:
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[†] A senior member of the research team must provide the explanation of and information concerning withdrawal from the research project.