



Participant Information Sheet

Title:	<i>Rural Firefighter Investigation of Risk & Exposure (R-FIRE): Brain Health</i>
Short Title:	<i>R-FIRE: Brain Health</i>
Project Sponsor:	<i>QIMR Berghofer philanthropic funding</i>
Principal Investigators:	<i>A/Prof Michelle Lupton, Dr Jodi Thomas</i>
Location:	<i>QIMR Berghofer Medical Research Institute (QIMR Berghofer)</i>

1. Why am I invited?

You are invited to take part in this research project, which is called the Rural Firefighter Investigation of Risk & Exposure (R-FIRE): Brain Health study. You have been invited to participate because you have had experience fighting bushfires (including prescribed burns or hazard-reduction burns) as either a paid or volunteer firefighter in Australia.

In this study you will be invited to fill out a firefighter-specific survey including questions about bushfire smoke exposure, personal protective equipment, and the health impacts of firefighting. You will then be invited to take part in another study, called PISA (the Prospective Study of Ageing). The PISA survey is designed to give us information on different factors, like brain health and cognition, that may contribute to healthy ageing, or age-related conditions such as dementia.

Completing both surveys will allow us to link your firefighting experiences with more detailed health and lifestyle information. With this information we will investigate how exposure to bushfire smoke and firefighting conditions may affect long-term brain health, and wellbeing.

This Participant Information Sheet/Consent Form tells you about the research project. It explains what is involved in taking part. Knowing what is involved will help you decide if you want to take part.

Please read this information carefully. Feel free to ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative or friend.

Participation in this research project is voluntary. If you do not wish to take part, you don't have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide you want to take part in the research project, you will be asked to sign the consent section. By signing it, you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described



2. What is the purpose of this research?

The aim of R-FIRE is to discover how bushfire smoke can impact brain health, particularly in Australia. Recent research has shown that air pollution, including bushfire smoke, can impact brain health. In particular, we want to know if smoke exposure can impact risk of developing age-related illnesses like dementia. Dementia refers to a group of age-related brain illnesses. People with these illnesses experience a gradual decline in how well they think and perform daily tasks. Currently, it is difficult to detect these illnesses at the very early stages of development. We also want to find out whether some people are at a higher risk of developing dementia than other people, and why that might be.

The information you provide if you choose to participate in the study may help us find out whether firefighters are at higher risk of age-related diseases than the general population. We hope to learn more about how bushfire smoke exposure affects the brain more generally as well. The findings may help guide future health advice, prevention strategies, and support for firefighters.

3. What does participation in this research involve?

You will be asked to complete an online questionnaire. The questionnaire can be filled out on a computer or an electronic device such as an iPad, tablet or phone. You will need to be able to access the internet with whichever device you choose. If you are unable to access the internet and would still like to participate in the questionnaire, please call 1800 257 179, and we will arrange a paper copy of the questionnaire to be sent to you.

The questionnaire will ask about your history of firefighting and exposure to bushfires. This questionnaire takes approximately 20 minutes to complete.

You will then be sent an email which will include more information about the PISA questionnaire, with a separate consent form. The PISA questionnaire asks about factors such as medical history, life experiences and health information. This more general questionnaire takes approximately 30 minutes. You do not have to complete the PISA questionnaire if you do not want to after completing the R-FIRE component.

You are welcome to withdraw at any time if participation becomes inconvenient or impractical.

4. What are the possible benefits of taking part?

This study is unlikely to be of any personal benefit to you. Although we cannot guarantee or promise that you will receive any benefits from this research, overall findings will potentially benefit patients with dementia if we are able to detect subtle changes in brain and behaviour earlier on. The study will also help improve our understanding of firefighter health, and may guide health advice and support for future generations of firefighters. We believe that many people will find participating in this study both enjoyable and interesting. We greatly value the time and effort that you give to research. This work would not be possible without the participation of volunteers.



5. What are the possible risks and disadvantages of taking part?

You may feel that some of the questions we ask you could be stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you do feel distressed during the questionnaire, you will be provided with crisis line and mental health support contact details within the questionnaire if you would like to talk to someone over the phone or online. Details for these services are also provided here:

Lifeline: **13 11 14**; www.lifeline.org.au

Beyond Blue: www.beyondblue.org.au

Black Dog Institute National Emergency Worker Support Service:
www.blackdoginstitute.org.au

6. What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. You can withdraw your consent by contacting the Project Coordinator by phone 1800 257 179 (free call) or email R-FIRE@qimrb.edu.au.

If you decide to leave the research project, personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with the law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project.

7. How do we protect your privacy and confidentiality?

All personal information collected for the study remains confidential in accordance with the National Health and Medical Research Council (NHMRC) ethical guidelines and the Privacy Act. We will not disclose any identifying information about you without your written permission, except to meet government, legal or other regulatory authority requirements. Your data file will have a number assigned to it, not your name. Your name will continue to be on file at QIMR Berghofer but will not be linked with your data. All personal details will be stored separately from data provided in the questionnaire. The only link between your data and your personal details is your participant identification number (meaning your data is potentially re-identifiable). Linking both your personal details and data file using this number is restricted to members of the QIMR Berghofer research team. A de-identified copy of this data, where your name, contact details and other identifying information are removed, may be used for other research purposes in the future.

Non-identifying questionnaire information will be collected via Qualtrics, a third-party survey host, and will be stored on Qualtrics servers for the duration of the study. No personal details



are stored with Qualtrics. These are all held separately on QIMR Berghofer servers in a password protected database.

The researchers will store your information indefinitely. This information may continue to be valuable to researchers many years into the future, and may be considered for use in future, related projects. Before any future work proceeds it will be subject to review by the relevant ethics committees. Results of this study might be reported in a scientific paper, but your identity will not be revealed. The data collected as part of this study will be combined at analysis, and as such there will be no way of identifying you as a participant.

In accordance with relevant Australian privacy and other laws, you have the right to request access to the personal information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of the document if you would like to access your information.

By confirming your consent online, you consent to the research team collecting and using personal information about you as described for the research project.

8. Will I be given the results of the research project?

This research is not intended for the purpose of treating any health problems you may have. Your information will be used for research purposes, and you will not be given any clinical results from this study. Your information will be analysed in aggregate with other participants in the study, and as such, the results are not individual and have no practical use.

Participation in this research study does not take the place of visits to a doctor or other health professionals.

9. Who is funding this research project?

This research has been initiated by the QIMR Berghofer Principal Investigator, Associate Professor Michelle Lupton. This study is being conducted in Australia by QIMR Berghofer. The research has been funded by a fundraising campaign run by QIMR Berghofer.

You will not benefit financially from your involvement in this study even if, for example, your data (or knowledge acquired from analysis of your data) prove to be of commercial value to QIMR Berghofer or the investigators.

In addition, if knowledge acquired through this study leads to discoveries that are of commercial value to QIMR Berghofer, there will be no financial benefit to you or your family from these discoveries.

No member of the study team will receive personal financial benefit from your involvement in this study (other than their ordinary wages).

10. Who has reviewed the research project?



All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been reviewed and approved by the HREC of the QIMR Berghofer Medical Research Institute (EC00278). This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

Should you wish to discuss the study in relation to your rights as a participant, or should you wish to make an independent complaint, you may contact the Secretary to the Chairperson of the Ethics Committee, Human Research Ethics Committee, QIMR Berghofer Medical Research Institute, Herston, QLD 4029, telephone (07) 3362 0117, or email HREC.Secretariat@qimrb.edu.au.

11. Who to contact

You are also free to discuss your participation in this study or any questions or concerns you have with the investigational staff listed below.

General queries: R-FIRE@qimrb.edu.au; or 1800 257 179

Project Co-ordinator:

Jessica Adsett
QIMR Berghofer
Herston QLD 4006
Email: jessica.adsett@qimrb.edu.au

Coordinating Principal Investigator:

Assoc. Prof Michelle Lupton
QIMR Berghofer
Herston QLD 4006
Email: michelle.lupton@qimrb.edu.au



Consent Form

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Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I understand that I will be given a copy of this documentation to keep.

I understand that information from this project will be stored indefinitely and may be considered for use in future related projects, subject to review by relevant ethics committees.

I freely agree to participate in the R-FIRE study as described in the Participant Information Sheet and understand that I am free to withdraw at any time during the project without affecting my future health care.

☐ Yes

☐ No

Signed by _____ (full name)

Dated: _____

I agree to be contacted about future, related studies and understand that I am in no way obligated to participate, and can freely withdraw this consent at any time without affecting my rights or the responsibilities of the researchers in any respect.

☐ Yes

☐ No