

# Privacy in the Hazelwood Health Study - Adult Survey and Health Record Linkage

The Hazelwood Health Study protects the privacy of participants in the Adult Survey in a number of ways:

- All participants are allocated an ID number in place of personal information such as name and address.
- Information we collect is entered into a de-identified database via the secure Hazelwood Health Study Adult Survey remote desktop.
- Access to this remote desktop portal is only made available to authorised Study staff via a password-protected and secure login.
- Data collected from participants is locked within a secure environment both physically (paper files) and electronically.
- All staff who are involved conducting in the Hazelwood Health Study Adult Survey have been trained and understand the importance of confidentiality and privacy.
- In addition, all Hazelwood Health Study staff have signed confidentiality agreements as part of their employment.
- Staff and contracted service providers who have been authorised to access data provided by the Victorian Electoral Commission (VEC) have signed a VEC confidentiality agreement, and would face severe penalties if they disclosed VEC data.

## Frequently asked questions about privacy and the Adult Survey

### *Why are the data being collected?*

The fire in the Morwell open cut mine adjacent to the Hazelwood power station blanketed Morwell and the surrounding area in smoke and ash for six weeks in February and March 2014. In response to community concerns about the long-term health effects, the Victorian Department of Health and Human Services (DHHS) commissioned the *Hazelwood Mine Fire Health Study*. The study is led by independent researchers from Monash University in collaboration with Federation University, University of Tasmania, University of Adelaide, and the CSIRO.

The *Hazelwood Health Study - Adult Survey & Health Record Linkage* will measure the long-term health of adults. This valuable study aims to address community concerns about the health impacts of the mine fire event and to provide evidence on which to base future health advice and services.

It is a large survey of all adults on the Victorian Electoral Roll who lived in Morwell, or targeted areas of Sale, at the time of the mine fire. Sale has been included as a comparison community which was minimally or not exposed to the smoke during the fire event.

In accordance with section 34 of the *Electoral Act (2002)*, the Victorian Electoral Commission has agreed to provide Monash University with an extract from the 2014 Victorian Election Electoral Roll including the names and addresses of people aged 18 years and over who resided in Morwell and Sale. An extract of the current Register of Electors has also been provided for the same electors including current address, whether the elector is still active on the roll and whether the elector is deceased. This information has been provided for the purpose of recruiting participants for the Adult Survey.

### *What will the data collected be used for?*

The data collected in the Hazelwood Health Study Adult Survey will provide valuable new information about long-term or chronic health conditions in Morwell residents and any associated impact of the mine fire smoke event. The findings will help inform the local community, their health-service providers and the State of Victoria Department of Health and Human Services (DHHS), of the long term health needs of the Latrobe Valley community.

### *Who will have access to my data?*

Only a limited number of trained Hazelwood Health Study personnel have access to information which may identify you, such as your name, address and telephone number. Every Hazelwood Health Study staff member and contractor has signed a confidentiality agreement as a condition of their employment.

Whilst the study is funded by the Department of Health and Human Services (DHHS), DHHS has **no** role in the collection, analyses and interpretation of participants' data, nor in the reporting of results.

The Hazelwood Health Study would never release your personal information to third parties without your specific consent, unless ordered to do so by a court order or by law.

### *How does the Hazelwood Health Study Adult Survey access my health records?*

It can be difficult for people to remember exactly when they used a health service, or the particular diagnoses received, and it may be difficult for us to contact you about your health in the future. For these reasons, Adult Survey participants are invited to give permission for the researchers to access their information from health databases such as ambulance, hospital, cancer and death records. The researchers would do this by linking a participant's name, date of birth and sex to these health records. For some linkages we also need the participant's Medicare Card number. This linkage will only occur with the participant's voluntary consent. Only medical information that is directly related to the study would be collected, de-identified, stored and analysed for the purposes of the Study.

Linkage to these health records may be repeated in the future if it remains scientifically informative to do so.

### *Will the information I provide remain confidential?*

Your answers to the questionnaire, and any of your information accessed through health record linkage, will be completely confidential.

All data will be stored in a secure, restricted-access area maintained by Monash University. The results of the study will be presented as grouped data which means that no individual participants could be identified.

### *How long will the Hazelwood Health Study Adult Survey keep information about me?*

All of the information gained in the Study will be held securely by Monash University for a period of five years after the completion of the Study in adherence with the National Health and Medical Research Council guidelines, University's regulations and various provisions of the Privacy Act 1988.

### *What happens to information about me if I die while I am still a participant in the Hazelwood Health Study Adult Survey?*

In that unfortunate event, information collected about Hazelwood Health Study participants would remain in the Study database, de-identified and kept for research purposes for a period of five years after the completion of the Study in adherence with the National Health and Medical Research Council guidelines, University's regulations and various provisions of the Privacy Act 1988.

### *Where is the information being stored?*

All electronic data will be held in a secure database cluster on a Monash University SQL Server (SQL Server 2008 R2), which will only be accessible to those granted user access via password secured login. Access to data is only granted to the specific project research staff requiring access in order to undertake the study. Database access is via a remote console login utilizing Remote Desktop Protocol (RDP) security, meaning that no data is transferred to the user's PC. Data of the nature involved with this study is classified as Critical and is thus stored and secured within the Red Zone on infrastructure under the management control of the, located within Monash University eSolutions Division.

### *Can I withdraw from the Adult Survey after consenting to take part?*

Being in this Study is voluntary and you are under no obligation to agree to take part. If you do participate, you can discontinue participation, or withdraw your consent to health record linkage, at any later date up to such time that your data has been analysed and included in final reports.

If you have any questions about participating in this study or wish to withdraw from the Study, please contact the Recruitment and Engagement Coordinator on freecall 1800 985 899 or by email at [recruitment@hazelwoodhealthstudy.org.au](mailto:recruitment@hazelwoodhealthstudy.org.au)

### *How do I make a complaint if I feel my information has been mishandled or there is a breach of privacy?*

If you feel your information has been mishandled or there is a breach of privacy please contact the Principal Investigator, Professor Michael Abramson at:

Monash University, Department of Epidemiology & Preventive Medicine,  
The Alfred Centre, 99 Commercial Road,  
Melbourne VIC 3004  
Tel: 03 9903 0573  
Email: [michael.abramson@monash.edu](mailto:michael.abramson@monash.edu)

If you have a complaint concerning the manner in which this study is being conducted, please contact the Executive Officer, Monash University Human Research Ethics Committee, and quote project number 2015/000389, at the following address:

Monash University Human Research Ethics Committee (MUHREC)  
Building 3e Room 111  
Research Office  
Monash University VIC 3800  
Tel: 03 9905 2052  
Email: [muhrec@monash.edu](mailto:muhrec@monash.edu)  
Fax: 03 9905 3831