

The personal information we hold should be accurate, complete and up-to-date. If at any time you believe that we hold incorrect personal information about you, please notify us and we will correct your personal information.

Who do I contact if I have questions or comments about this Privacy Statement?

In the first instance discuss the matter with the researcher with whom you have contact. In most cases they should be able to answer your questions or direct your question to the appropriate staff member within the Woolcock Institute of Medical Research. In addition, you can contact our General Manager who has responsibility for privacy issues.



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PRIVACY STATEMENT

Your
questions
answered



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What is this statement about?

Commonwealth and State Privacy Laws require us to have procedures to ensure the privacy of personal information. In medical research we are especially aware that some of the information we collect may be sensitive. At the Woolcock Institute of Medical Research we have effective procedures and trained staff who work hard to ensure we maintain the highest level of confidentiality.

To satisfy these Privacy Laws we must tell you;

- a) What personal information we collect and why we collect this information
- b) How we ensure the privacy of your personal information
- c) Who we share your personal information with and
- d) How you can access your personal information

What personal information do we collect and why do we collect this information?

Medical research depends on the goodwill of people like you sharing information about your health. We may ask questions about your health, personal situation, diet, visits to the doctor or hospital or any medicines you take. Depending on the purpose of the research we will collect different information to help us answer a specific research question.

For example, a study of risk factors for asthma might include questions about a child's asthma and about the child's home environment and diet. A study on emphysema might include questions about current lifestyle and lifetime exposure to cigarette smoke.

The information collected assists us to look for links to better understand what causes disease, what improves management of a disease and what can lead to remission of disease. At any time you can decide not to answer a question or share a particular piece of personal information. You will not be forced to provide information. However, we do hope that you will provide as much information as possible to assist our research.

How do we ensure the privacy of your personal information?

Confidentiality of your personal information is one of our primary concerns. Whenever possible we use forms and questionnaires that identify you by a unique ID number. Some forms or questionnaires may require identifying personal information such as name and address. All forms and questionnaires are stored in a locked area and information that is stored electronically is kept on a secure password protected computer system.

We do not hold your personal information indefinitely. The information will only be held for the period recommended by research practice guidelines. Current guidelines recommend research institutions maintain records for 15 years after publication of the most recent research report.

Do we share your personal information?

We do not share your personal information with anyone other than people or organisations directly involved in the research. When you agree to participate in a study you will be made aware of who is responsible for the study, who is working on the study and who is providing funding for the study. Access is strictly limited to those people directly involved in the research.

As part of your participation in our research we may collect information that is useful for your doctor to keep on file. We are able to provide a copy of your results to your doctor but we will only do this at your request.

How can I gain access to my personal information?

You can request access to your personal information by contacting the researcher who collected the information or by contacting our General Manager. If you write to us please provide details of exactly what information you require. If you contact us by telephone we may ask you some personal questions to identify you and ensure the confidentiality of your information.