



Doc-ID PCS-001

Privacy Collection Statement (Clinical Trials and Data Registries for Research)

This Privacy Collection Statement (Clinical Trials and Registries for Research) explains the circumstances in which personal information is collected from individuals with respect to Clinical Trials and Data Registries for Research that Lung Foundation Australia have a responsibility for.

1. Introduction

- 1.1 Lung Foundation Australia Limited ACN 160 505 671 ("**the Lung Foundation**") (in this Privacy Collection Statement also called "we", "us" and "our") is an Australian registered charity supporting research, providing education services, undertaking community awareness activities and advocacy around Australia in relation to lung health.
- 1.2 We respect the privacy of the personal information you may provide to us. The way in which we manage your personal information is governed by the *Privacy Act 1988* (Cth) (**Privacy Act**) and the Australian Privacy Principles (**APPs**) established under the Privacy Act and the Lung Foundation Privacy Policy (www.lungfoundation.com.au/privacy-policy).
- 1.3 For the purposes of this Privacy Collection statement, "personal information" has the meaning given to it in the Privacy Act, being information or an opinion about an identified individual, or an individual who is reasonably identifiable, whether the information is true or not, and whether the information or opinion is recorded in a material form. Examples of personal information include an individual's name, address, telephone number and date of birth.

2. Collecting your personal information

- 2.1 Before collecting personal information for clinical trials and data registries for research, you will be asked to complete a Consent Form, which will:
 - (a) explain the specific purpose(s) for which your personal information is being collected;
 - (b) outline the process that you will be asked to complete to participate in the clinical trial or data registry; and
 - (c) allow you to confirm your permission for your personal information to be collected for the purpose(s) outlined.
- 2.2 We collect your personal information so that we can:
 - (a) develop a database of persons who have indicated that they are willing to participate in clinical trials or data registries, that might be initiated by Lung Foundation Australia or another third party;
 - (b) communicate information about specific clinical trials that might be suitable for your participation and to issue Consent Forms which would be used by you to confirm your participation in a clinical trial or data registry;



- (c) include the personal information in a data registry (usually for specific disease types) that is made available for research being conducted by external researchers, with the data having being de-identified before it is released;
- (d) provide you with any questionnaires or forms that require your completion to update your information on the clinical trial or data registry or to follow up on the personal information contained in the clinical trial or data registry;
- (e) communicate information about the activities, campaigns, programs, education courses and fundraising being undertaken by the Lung Foundation, either by a newsletter or other form of communication; and
- (f) take any other action related to the above or otherwise necessary to give effect to your participation in a clinical trial or data registry.

2.3 The kinds of personal information we collect from you include:

- (a) your name;
- (b) your address details;
- (c) your email address;
- (d) your telephone and / or mobile phone numbers;
- (e) the name of your doctor and/or treating physician(s);
- (f) your disease type and medical history, including medical test results; and
- (g) information about your environment and family history.

2.4 Wherever possible, we will collect your personal information directly from you, through consent forms, phone interviews or questionnaires specific to the clinical trial or data registry or from your doctor and/or treating physician(s), for which your consent will have been requested and obtained through the completion of the Consent Form.

2.5 We will not otherwise collect sensitive information from you, such as your medical information, unless we have your consent to do so and the collection of such information is reasonably necessary for our functions and activities.

2.6 Before personal information collected by Lung Foundation Australia for a clinical trial or data registry is provided to an external party for research, the information will be de-identified so that the external party is not able to trace the personal information back to you. It is possible that you will be given an opportunity to communicate directly with the external third party, but this will be provided through a process conducted by the Lung Foundation, which (if you consent) will allow you to initiate direct communication with the external third party.

2.7 Once your personal information has been collected, it will be stored in a data repository that will be located in Australia in most cases. In the case, where the data repository is located at an overseas location, either USA or United Kingdom, your personal information will be stored as de-identified data and will only be accessed by specific staff of the Lung Foundation or one of the Principal Investigators that are members of the Management Committee for the registry for which the personal data has been collected. Your personal



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information will not be able to be accessed by persons outside of Australia unless your personal information has been de-identified and their request for access to data for research has been approved by the Registry Management Committee.

3. **What happens if we don't collect your personal information?**

3.1 If we do not collect your personal information or you only provide some of the personal information we request, then the Lung Foundation:

- (a) may not be able to include your details in the clinical trial or data registry that you wish to participate in, which means that you will not be able to participate in the clinical trial or data registry;
- (b) may not be able to contact you at the time that your personal information needs to be updated, if this is a requirement of the clinical trial or data registry; and
- (c) may not be able to communicate information about the activities, campaigns, programs, education courses and fundraising being undertaken by the Lung Foundation, either by a newsletter or other form of communication.

4. **Disclosing your personal information**

4.1 In providing our services and carrying out our functions and activities listed above, we may disclose your personal information to:

- (a) our employees; and
- (b) your de-identified personal information may be disclosed to an external third party that is conducting a clinical trial or data registry when the Lung Foundation receives notification from you that you wish to participate in a clinical trial or data registry.

4.2 The disclosure of your personal information will be in a de-identified form and will be subject to a non-disclosure agreement with an external third party. The external third party may in turn disclose your de-identified personal information to other entities as described in their respective privacy policies or notices (e.g. if required by legislation to do so).

5. **Disclosing personal information overseas**

5.1 Information that you provide to the Lung Foundation with respect to clinical trials or data registries may be disclosed in a de-identified form to an overseas party only if that overseas party is conducting research on the data collected for the clinical trial or data registry. The overseas party may be located in USA, United Kingdom or Europe.

5.2 Before your personal information is disclosed, it will be de-identified so that the overseas party is not able to trace the personal information back to you.

6. **Accessing and correcting your personal information**

6.1 The Lung Foundation Privacy Policy (www.lungfoundation.com.au/privacy-policy) provides further detail on how we manage your personal information, including how you can:

- (a) request access to, or seek correction of, the personal information we hold about you; and



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- (b) lodge a complaint relating to a breach of the APPs and how we will deal with such a complaint.

7. **Our contact details**

7.1 If you wish to contact us regarding our handling of your personal information or any of the matters covered in this Privacy Collection Statement, please contact our Director of Operations at:

- (a) Telephone – 61 7 3251 3600
- (b) Email – finance@lungfoundation.com.au
- (c) Online – www.lungfoundation.com.au/privacy-policy
- (d) By post – Lung Foundation Australia, PO Box 1949, Milton, QLD 4064

7.2 Alternatively you may contact the general enquiries line on 1800 654 301 (for enquiries within Australia) or +61 7 3251 3600 or lodge an enquiry by emailing enquiries@lungfoundation.com.au.

8. **Your Acknowledgement and Consent**

8.1 By continuing to correspond or interact with us or by providing us with your personal information, you are taken to have read and understood this privacy collection statement and you have consented to us managing your personal information as described in this privacy collection statement and our privacy policy.