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Using drawings to further understanding of people's perceptions and experiences of their asthma

PARTICIPANT INFORMATION STATEMENT

(1) What is this study about?

You are invited to take part in a research study exploring the use of drawings to further understanding of people's perceptions and experiences of their asthma.

You have been invited to participate in this study because you have asthma. This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the study. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary.

By giving consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

(2) Who is running the study?

The study is being carried out by the following researchers:

- A/Prof Lorraine Smith, Associate Professor, Faculty of Pharmacy, the University of Sydney
- Dr Bandana Saini, Senior Lecturer, Faculty of Pharmacy, the University of Sydney
- Melissa Cheung, PhD candidate, Faculty of Pharmacy, the University of Sydney

Melissa Cheung is conducting this study as the basis for the degree of Doctor of Philosophy at the University of Sydney. This will take place under the supervision of A/Prof Lorraine Smith, Associate Professor and Dr Bandana Saini, Senior Lecturer.

(3) What will the study involve for me?

You will be asked to complete a survey, a lung function measurement, an interview and a drawing activity. This will be conducted in one sitting, in-person with a researcher at a location convenient to you and the researcher.

- The survey is self-reported and measures illness perceptions, asthma control, health status and asthma management.
- A spirometry reading measuring lung function will be performed by a trained health professional. Spirometry is a safe and relatively quick test recognised as an essential clinical tool in the diagnosis and management of respiratory conditions. You will be required to breathe in fully and exhale as fast and as far as possible into the measuring equipment until your lungs are empty. The spirometry results will be available immediately and you will be given a copy of this for your records.
- The interview will involve questions about your perceptions and personal experiences of asthma.
- You will be asked to draw how asthma affects you. Drawing materials (paper and pens) will be provided. You will be asked to describe your drawing and provide feedback about how you felt about the drawing activity.

The survey and drawing will be returned immediately after completion and the interview and discussions about your drawing will be audio recorded for the purpose of data analysis.

(4) How much of my time will the study take?

The total time commitment is expected to be approximately one hour.

(5) Who can take part in the study?

You can take part in this study if you are over 18 years of age and have been told by your doctor that you have asthma.

(6) Do I have to be in the study? Can I withdraw from the study once I've started?

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Sydney.

If you decide to take part in the study and then change your mind later, you are free to withdraw at any time. You can do this by contacting A/Prof Lorraine Smith at the Faculty of Pharmacy, the University of Sydney on 02 9036 7079 or by emailing lorraine.smith@sydney.edu.au.

You are free to stop your involvement and the interview at any time. Unless you say that you want us to keep them, any recordings will be erased and the information you have provided will not be included in the study results. You may also refuse to answer any questions that you do not wish to answer during the interview.

(7) Are there any risks or costs associated with being in the study?

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

(8) Are there any benefits associated with being in the study?

At completion of your participation in this study, you will receive a \$50 gift voucher.

(9) What will happen to information about me that is collected during the study?

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

Your information will be stored securely and your identity/information will only be disclosed with your permission, except as required by law. Study findings may be published, but you will not be identified in these publications.

Your answers to the survey, your spirometry reading, interview audio recording and drawing will be collected, however your identity will be deleted.

(10) Can I tell other people about the study?

Yes, you are welcome to tell other people about the study.

(11) What if I would like further information about the study?

When you have read this information, A/Prof Lorraine Smith will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact A/Prof Lorraine Smith at the Faculty of Pharmacy, the University of Sydney on 02 9036 7079 or by emailing lorraine.smith@sydney.edu.au.

(12) Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by ticking the relevant box on the consent form. This feedback will be in the form of a one page lay summary. You will receive this feedback after the study is finished.

(13) What if I have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney (protocol number: 2015/876). As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** ro.humanethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

This information sheet is for you to keep