

PARTICIPANT INFORMATION SHEET

ETH23-8041 – Legal Needs of People Living with a Communicable Disease: A Mixed-Methods Socio-Legal Study

WHO IS CONDUCTING THIS RESEARCH?

My name is David Carter, and I am an academic at the University of New South Wales. With Anthea Vogl at the University of Technology Sydney, we are leading a research project with a group of other researchers at UTS in the Faculties of Law, Health and Science.

WHAT IS THE RESEARCH ABOUT?

The purpose of this research is to better understand the legal issues and needs facing Australians and how these impact on their health and quality of life.

WHY HAVE I BEEN INVITED?

You have been invited to participate as you have some relevant experience or expertise that will be valuable for this research study.

Before you decide to participate in this research study, we will discuss the selection criteria with you.

Your contact details were obtained by a referral from your lawyer or community organisation or you self-referred from an advertisement or flyer. Participation in this research is entirely voluntary, and your lawyer will not know whether you have decided to participate or not unless you choose to tell them.

FUNDING

Funding for this project has been received from the Australian Government, Department of Health and Aged Care.

WHAT DOES MY PARTICIPATION INVOLVE?

If you decide to participate, we will invite you to participate in a 40-70 minute long semi-structured interview on the telephone or over video conferencing, that will be audio recorded and transcribed. We will use this transcript as a record of our interview and for analysis. The interview will cover a number of topics, focused on your own experience of legal needs and issues in the past. You must be aged 18 years or older to participate in this research.

Interviews will be primarily conducted in English, however, in some circumstances we may be able to conduct an interview in a language other than English. If you prefer to be interviewed in a language other than English, please contact the researcher to see if this is possible.

You will be offered a gift card to thank you for your participation in this research. The value of this gift card will be \$50. If you wish to receive the gift card, it will be provided to you via email approximately two business days after you have completed your interview. It can be used across Australia at a variety of stores.

ARE THERE ANY RISKS/INCONVENIENCE?

Yes, there are some risks and inconvenience.

You might be asked questions that are sensitive, such as questions about past legal issues or needs that you have experienced, or regarding your health or health status. You may find some of our questions bring up feelings of discomfort or distress, regarding your experience of legal issues in the past. To help reduce the chance of this occurring, we will be using open-ended and exploratory questions, so you can simply elect to not discuss or disclose information or issues that you do not wish to.

You might find the effort required to participate in the research ceases an inconvenience. If at any time before, or during the research you decide that you wish to stop the research activity you are absolutely welcome to do so.

You might be concerned regarding the confidentiality of your responses and other information you share. If you choose to participate, we will not ask for your name or other identifying information. We will not record your name or other identifying information. Any publications or discussion regarding this research will use a pseudonym rather than your own name.

You may feel you have to participate because you have been told about the study by your lawyer. Rest assured, you do not have to participate in this research. If you choose not to participate, we will not let anyone know about your decision. This will not affect your relationship with the researchers, your lawyer, the University of Technology Sydney or the University of New South Wales.

DISCLOSURE OF ILLEGAL ACTIVITY OR CRIMINAL VICTIMISATION

This research is investigating the legal needs and issues that have arisen for people. This can include legal needs or experiences relating to any area of law, including criminal law.

We will not ask you to discuss, or provide details, regarding your legal needs or problems that you do not wish to discuss. Instead, you should choose to answer the question, or provide information, only as you feel comfortable. You may simply leave out details or any information you wish not to discuss.

We will generally not disclose information without your consent but there may be circumstances where we have to do so for legal reasons. In that case, the information could potentially be used against you in legal proceedings or otherwise.

You should not tell us anything specific about events or activities such as potentially illegal or criminal activity. Please don't tell us things like names, specific dates or specific places of potentially illegal or criminal activities.

DO I HAVE TO TAKE PART IN THIS RESEARCH PROJECT?

Participation in this study is voluntary. It is completely up to you whether or not you decide to take part.

If you decide not to participate, or to withdraw from the study, it will not affect your relationship with the researchers, the University of Technology Sydney, the University of New South Wales, your lawyer or community organisation who may have referred you.

WHAT IF I WITHDRAW FROM THIS RESEARCH PROJECT?

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason, by contacting David Carter (david.carter@unsw.edu.au). If you withdraw from the study, any data collected about you will be destroyed including recordings or transcripts. However, it may not be possible to withdraw your data from the study results if these have already had your identifying details removed.

WHAT WILL HAPPEN TO INFORMATION ABOUT ME?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. All this information will be treated confidentially. It will be stored in electronic format, with password protection, on UTS servers.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your permission. To achieve this, we will remove any identifying information from the information stored about you. For example, we will use a pseudonym instead of your real name.

We would like to store your information for future use in research projects that are an extension of this research project. In all instances, your information will be treated as confidential and stored securely.

In accordance with relevant Australian and/or NSW Privacy laws, you have the right to request access to the 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 this document if you would like to access your information.

WHAT IF I HAVE ANY QUERIES OR CONCERNS?

If you have queries or concerns about the research that you think we can help you with, please feel free to contact David Carter on david.carter@unsw.edu.au or Anthea Vogl on anthea.vogl@uts.edu.au. You can also speak to a local independent contact: Ms A Stratigos on (02) 9206 2060.

If you have any questions about the law, your rights or a particular legal issue you would like to discuss with someone following this interview, you should either contact David Carter on david.carter@unsw.edu.au or Ms A Stratigos on (02) 9206 2060 who can refer you to a lawyer to discuss your questions with free of charge.

You will be given a copy of this form to keep.

NOTE:

This study has been approved in line with the University of Technology Sydney Human Research Ethics Committee [UTS HREC] guidelines. If you have any concerns or complaints about any aspect of the conduct of this research that you wish to raise independently of the research team, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au, and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

CONSENT FORM

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I

agree to participate in the research project being conducted by Dr David Carter and colleagues at UTS and UNSW (david.carter@unsw.edu.au; (02) 8936 7005). I understand that funding for this research has been provided by The Australian Government, Department of Health and Aged Care.

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 as described in the Participant Information Sheet.

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

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time without affecting my relationship with the researchers or the University of Technology Sydney.

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

I am aware that I can contact Dr David Carter or Ms A Stratigos on (02) 9206 2060 if I have any concerns about the research.

The following are two items you may select. They are completely optional.

I would like to be emailed updates regarding the results of this research to this email address:

I would like to be contacted if other opportunities for participating in research arise that are an extension of this research project via this email address:

Name and Signature [participant]

____/____/____
Date

Name and Signature [researcher or delegate]

____/____/____
Date