

Participant Information Sheet

Title of Research Project: *Attitudes towards organ donation and transplantation* 2009

Dear prospective study participant,

We invite you to take part in a study interviewing New Zealanders about beliefs and perceptions of organ donation and transplantation.

This research project has several objectives. First, the study is designed to document the experiences of organ donors, donor families, and organ transplant recipients. We would also like to talk to people who have been offered the option of donating the organs or body tissues of a family member and have decided against this. Second, the study will examine the suitability of current language and vocabulary used to describe organ transfer procedures in health care settings and in the public domain. The overall aim of the study is to engage people in discussion and to contribute New Zealand data to our understanding of decision-making around organ donation and transplantation. It is intended that results from this study will be published in academic journals, and findings will be discussed at academic conferences, in the media, and within community groups. With your consent, data from the study will be incorporated into a larger study on giving and receiving body tissues and organs at a later stage.

The research project is divided into several parts. This part of the study will involve talking to people in face-to-face interviews about their part in organ donation and transplantation procedures, so we are especially interested to talk to individuals or to families who have had personal experience of organ donation and/or transplantation.

We will commence interviewing people in October 2008 and will complete data collection for this part of the study in 2009. Participation in the project is entirely voluntary. You can pull out of the study at any time prior to the completion of data gathering and also withdraw identifiable information up to one month after taking part in an interview. If you agree to participate in the research, we anticipate the interview will take between 1 to 2 hours total, depending on your availability. To our knowledge, the nature of the questions we will ask will be such that you are unlikely to experience any discomfort as a result of taking part in the study. However, if you do experience discomfort you can stop the interview at any time.

We would prefer to audio tape the interview, but if you are not comfortable with that then this is not essential. The interview will only be audio taped with your written consent. We would be happy to come to your place of work or your home for the interview. The interview will be transcribed, and all details that could identify you will be removed. If you would like to check your interview transcript before data analysis, please let us know. The data will be published in such a way that you will not be able to be personally identified, although institutional details of transplant units in New Zealand will be documented in publications (e.g., academic articles and books, conference papers, media reports) resulting from the study. You will be given the opportunity to request a summary of findings at the end of the research.

The interview files and transcripts will be kept in a secure cabinet in a locked office in the School of Social & Cultural Studies at Victoria University or the School of Social Sciences at Auckland University of Technology, and on computers to which only the researchers, Dr. Rhonda Shaw and Dr. Robert Webb, have access.

If you identify as New Zealand European or Pakeha and would like to be involved in this study please contact Dr. Shaw by telephone on (04) 463 6134 or by email at rhonda.shaw@vuw.ac.nz so that we can decide on a time and place to talk. If you identify as Maori and would like to be involved in this study please contact Dr. Webb by telephone on (09) 921 9999 ext. 7901 or by email at robert.webb@aut.ac.nz.

We would also like you to sign a consent form that says you are happy for us to use the information you provide. The consent form can be signed prior to the interview. Please let us know if you would like the consent form written in Maori or in a language other than English, and if you would like an interpreter for the interview.

We look forward to hearing from you, and thank you for your interest in this project.

Yours sincerely

Dr. Rhonda Shaw

This study has received ethical approval from the Multi-Region Ethics Committee which reviews National and Multi-regional studies (MEC/08/03/027).

For any queries regarding ethical concerns and your rights as a participant in this research you can contact an independent health and disability advocate. Telephone (NZ wide): 0800 555 050. Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT). Email: advocacy@hdc.org.nz

Compensation

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assessed by ACC according to the provisions of the 2002 Injury Prevention Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators. If you have any questions about ACC, contact your nearest ACC office or the investigator.