



Participant Information Sheet

Source Attribution Campylobacter New Zealand Study (SACNZS)

Study title: SACNZS

Locality: Auckland and MidCentral Public Health Service Regions

Lead investigator: Dr Donald Campbell, Ministry for Primary Industries

Dear XXXX,

We are conducting a study on the bacterial infection campylobacteriosis via a telephone survey. When you participated in the New Zealand Health Survey recently, you agreed that the Ministry of Health could re-contact you for further health research. We are selecting members of the Health Survey group from the two relevant regions (Auckland and Manawatu/Whanganui) to act as controls (i.e. unaffected people) for the study.

This letter is to inform you that you MAY be contacted to participate in the study.

Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason. If you do decide to take part now, you can still decide to pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It explains why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what will happen after the study ends. We have sent you this information and, if required, are available to answer any questions you may have. We expect the survey will take up to 25 minutes depending on how many questions you answer. You may also want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

What is the survey about?

The results from the survey will be used in a nationwide study to compare the habits and experiences of a group of people who have recently become sick with an infection from a bacteria (cases) with the habits and experiences of a group of people who have not recently had this illness (controls). Habits and experiences that are more common amongst cases than controls are called risk factors and may be causes of infection.

Why is this survey important?

Campylobacteriosis is an illness caused by a bacteria. In New Zealand, every year, about 60,000 people, and particularly children, become ill from this bacteria and we would like to

know why. The information you provide will help us to understand the causes of this illness so that measures can be put in place to reduce the number of people getting sick.

Who is carrying out the survey?

The Ministry for Primary Industries is leading this research, with participation of Massey University, the Institute of Environmental Science and Research (ESR, a Crown Research Institute), and two Public Health Services covering five District Health Boards.

What sort of questions will be asked?

You will be answering questions during a phone call that will cover aspects of your contact with animals or ill people, travel, food and water you have consumed and activities you may have taken part in for up to 2 weeks ago.

How long will the telephone survey take?

The telephone survey will take 15-25 minutes depending on how many of the questions are relevant to you. We will schedule appointments to call at a time that is convenient. Please let your household members know that UMR Research will be calling to schedule an appointment with you.

Risks and benefits of the study

While there will be no risks to you from participating in this study, unfortunately there will be no immediate benefits to you either. People usually find the questions quite interesting. You do not have to answer any questions you do not wish to answer, and you can stop the interview at any time. The results from our study will help to guide policy efforts in New Zealand at a national level, so we can prevent people from becoming ill in the future. So the anticipated benefits to the scientific community and society are high.

How many times will I be asked to participate in the survey?

For this particular survey, we will only ask you to participate once. You can withdraw from the study at any time.

Confidentiality and Security of Data

The information you provide to the interviewer is confidential and the study organisers guarantee that storage of your information will be in accordance with the requirements of the Privacy Act 1993. This is also a requirement of the Health and Disabilities Ethics Committee approval. Like the New Zealand Health Survey, the answers you give in this survey will be added to other people's answers to create an anonymised dataset. This means that your name is not included and no one will be able to identify you by looking at your answers. The dataset will be stored securely at the Institute for Environmental Science and Research Ltd.

Your name and contact details will be kept in another secure file, separate from the survey answers, with strictly limited access. The purpose of recording these details is to know who has been contacted, so that your participation can be recorded by the Health Survey population, and you will not be contacted again for such additional studies.

Participants will not be identifiable in any of the reports or presentations of findings from this survey.

Where can I find survey results?

The plan is to publish the results of this study, as a study report, by the end of 2019 and subsequently as scientific papers. The report will be available on the website:

www.sacnzs.org.nz

What will the information be used for?

The information gathered from this survey will be used to inform and improve policy in order to reduce the number of infections from Campylobacter bacteria nationally in New Zealand.

Who has funded this survey?

The study is being funded by the Ministry for Primary Industries (MPI).

What if I don't want to participate?

Participation is completely voluntary and you may decline to participate, or withdraw from the study at any practicable time, without experiencing any disadvantage. The study will not collect any information about you other than the information provided by you during the interview.

Has the study received ethical approval?

Yes, this project has been reviewed and approved by the Health and Disability Ethics Committee

Where can you go for more information about the study, or to raise concerns or complaints?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Dr Rob Lake
Manager, Risk and Response Group, ESR
Phone: 03 3516019
Email: rob.lake@esr.cri.nz

A lay-person summary of the study design can be requested from Rob Lake.