**Participant Information Sheet for cases**

CampySource—Understanding the Sources of *Campylobacter* in Australia

The Australian National University, in conjunction with state and territory health departments and other research institutes, is conducting a study of *Campylobacter* infection in Australia to identify possible causes. *Campylobacter* infections are notifiable to health departments in each state and territory throughout Australia.

The research team is collecting information through phone interview of people diagnosed with *Campylobacter* infection who live in Queensland, Hunter New England, and the Australian Capital Territory to answer questions about their illness and foods they ate before their illness. For the purpose of comparison, the research team will be also interviewing people who did not become ill with the bacteria. Genetic data obtained from *Campylobacter* isolated from humans, food, and pets will be combined with the information obtained through phone interviews to help identify causes of infection with *Campylobacter*.

**Who is in the research team?**

The National Centre for Epidemiology and Population Health is one of Australia’s leading health research centres. The team for this study will involve international experts in epidemiology, whole genome sequencing, and mathematical modelling. Associate Professor Martyn Kirk and Associate Professor Kathryn Glass will lead the study. More than 28 different experts from more than 21 institutions are involved in this research project.

**How will you use my data?**

The information collected from the interviews will allow us to identify risk factors for infection with *Campylobacter*. The results from this study will inform measures to reduce human illness from *Campylobacter* in Australia. Any reports resulting from this study will be published on the study webpage <http://nceph.anu.edu.au/research/projects>.

Results will be summarised in a way that no individual could be identified in any published material.

**How can I participate in this study?**

Your participation in this study is voluntary. You can refuse to answer any question, or finish the interview at any time. Your refusal to participate in the study will not have any negative consequence. If you withdraw from the study, your information will be destroyed and will not be used in the study. If you decide to be involved in the study, you will be interviewed about overseas travel; water consumption; dining locations outside of the home; consumption of fresh produce; meat and poultry consumption; seafood consumption; consumption of eggs and dairy products; animal and pet exposures; and demographic information. Since we would like to find out more about *Campylobacter* illness, you will be also asked additional questions about the clinical course of your illness and any treatment you had for it. Your response will be anonymously recorded in a questionnaire prepared for this purpose, and it will be accessible only by the research team.

The phone interview will take approximately 20 minutes.

**Are there any risks in participating?**

Participating in this study does not have any anticipated risk. Providing information about your clinical illness may create some discomfort. However, the interviews do not touch on any sensitive personal medical history, apart from the clinical illness.

**What are the benefits to participants?**

This study aims to provide a clearer understanding of the cause of *Campylobacter* infection. The results will provide evidence for health and food safety agencies’ efforts to prevent, control, and reduce the risk of *Campylobacter* infection to the public.

**Am I eligible to participate?**

Interviews will be conducted with people who recently experienced an illness due to the *Campylobacter* bacteria and reside in Queensland, Hunter New England NSW, or the Australian Capital Territory. To be able to collect information that will help us to identify possible cause of Campylobacter infection, you, or a child you are responding on behalf of need to fulfil the following criteria:

* Having an illness consisting of 3 or more loose stools in 24 hours and able to provide us the date that the diarrhoea began;
* Have not had anyone in your household who was unwell with diarrhoea or have tested positive to *Campylobacter* in the 4 weeks prior to your illness; and
* Have not travelled overseas in the 2 weeks prior to the illness.

**How will you protect my identity?**

Your privacy is important to us. No identifying information will be released. Data from individual participants are labelled with a unique identification number that has no external meaning and can only be linked back to identifying participant information using a correspondence file, which is accessible only to the public health units. Analyses will be undertaken on datasets with personal identifiers removed. Thus, you will not be identifiable in any reports or publications. In addition, computerised data will be stored in a secure university server environment with password protection. The only people with access to the data will be those listed on this proposal as primary and co-investigator. The data will be destroyed five years after final publication, in accordance with ANU policy. Confidentiality will be protected as far as the law allows.

Isolate information containing individually identifiable data will be accessed and used in secure computing environments used at Queensland Health, Microbiological Diagnostic Unit Public Health Laboratory, or Hunter New England Health. Analysis outputs will only contain re-identifiable data or non-identifiable data.

In collecting your personal information within this research, the ANU must comply with the Privacy Act 1988. The ANU Privacy Policy is available at https://policies.anu.edu.au/ppl/document/ANUP\_010007 and it contains information about how you can:

* Access or seek correction to your personal information;
* Complain about a breach of an Australian Privacy Principle by ANU, and how ANU will handle the complaint

**Questions about the research study**

If you have any questions, do not hesitate to contact us by email or phone:

Associate Professor Martyn Kirk Associate Professor Kathryn Glass

T: (02) 6125 5609 T: (02) 6125 2468

E: [martyn.kirk@anu.edu.au](mailto:martyn.kirk@anu.edu.au) E: [Kathryn.Glass@anu.edu.au](mailto:Kathryn.Glass@anu.edu.au)

**Concerns or complaints about the research study**

The ethical aspects of this research have been approved by the ANU Human Research Ethics Committee (Protocol 2016/426). If you have any concerns or complaints about how this research has been conducted, please contact:

Ethics Manager  
The ANU Human Research Ethics Committee  
The Australian National University  
Telephone: +61 2 6125 3427  
Email: [Human.Ethics.Officer@anu.edu.au](mailto:Human.Ethics.Officer@anu.edu.au)