PARTICIPANT INFORMATION LEAFLET (PIL)

1. Introductory statement – invitation to take part

UCD Centre for Veterinary Epidemiology and Risk Analysis (CVERA) would like to invite you to take part in a research study. This Participant Information Leaflet and Consent Form tell you about the study. It explains what is involved if you agree to take part. Knowing what is involved will help you decide if you want to take part in the research. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether to take part, you might want to talk about it with a relative, friend or healthcare worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent form at the end of this document. By signing it you are telling UCD CVERA that you:

- understand what you have read.
- consent (agree) to take part in the research project.
- consent to participate in the research processes that are described.
- understand how your personal data will be used.

2. Contact details:

Dr Katie Corridan

Centre for Veterinary Epidemiology and Risk Analysis

University College Dublin

Bellfield

Dublin 4

Katie.corridan@ucd.ie

0858007779

3. Title of the research

Q Fever in Ireland: Characterising Zoonotic Risk

4. What is this research about? / Why is this study being done?

We are studying Q fever, a disease that can sometimes spread from animals to people. Our goal is to learn how common Q fever antibodies are in different areas and among people with different jobs (such as those which involve contact with farm animals). This will help us understand how the disease spreads and improve our recognition and detection of the disease.

This project allows the prevalence of Q fever to be recorded and represented in scientific literature for future reference.

5. Why have I been invited to take part?

You have been invited to take part because you are in working in a particular profession, such as those who have contact with farm animals and/or are in a particular location.

6. Do I have to take part?

No, you do not have to take part in this study. It is your choice. You do not have to give a reason for not taking part in this study.

7. What will happen if I decide to take part in this research study? What do I need to do?

If you agree to participate, you will be asked to:

Provide a Small Blood Sample: A trained professional will take a small blood sample (approximately 5ml) in our mobile clinic.

The blood test checks for antibodies to Q fever. This is not a screening test, a positive result indicates that you have been exposed to Q fever at some point, which may have been many years ago. If you subsequently develop symptoms and are concerned, please contact your GP or healthcare provider.

In addition to the blood sample, you will be asked some questions such as your age category and if you have contact with farm animals.

Your participation is voluntary. If you initially decide to take part, you can change your mind without difficulty.

8. Can I withdraw from the study? What happens if I change my mind?

You can change your mind about continuing participation at any time without giving a reason. There are no negative consequences if you choose not to continue to take part in this research study. If you wish to withdraw from this research study, please contact Dr Katie Corridan, (katie.corridan@ucd.ie, 01 716 6144) who will be able to organise this for you.

If you choose to withdraw, any data you have provided will be securely deleted so that it will no longer be part of the study going forward, and there will be no consequences for your decision. While the project will make every effort to delete your data, there are limits to this being possible. For example, if the data have been fully anonymised and the researchers can no longer tell which is your information within the dataset; if the data was already analysed

and forms part of the scientific research findings; or where de-identified data is part of a scientific document already published.

9. What are the benefits of my participation in this research: to me, to the researchers, and to any third parties involved?

Taking part in this study may not directly benefit you. However, UCD CVERA hope that this research may help to better understand Q fever and may result in new policies and guidelines. By participating, you'll help generate essential evidence on Q fever—a little-understood zoonotic disease—to inform both public health and animal health interventions. Your contribution will support strategies that protect people, livestock, and communities for the greater public good.

The researchers may benefit from completion of this research study in terms of award of MD degree and publications. The research team hopes to publish a paper based on the findings of this study. This research has been funded by the Department of Agriculture, Food, and the Marine.

10. What are the risks of taking part in this research study?

There is minimal risk associated with participation in this study.

Blood will be collected from a vein in your arm in the same way that blood samples are normally taken. As a result of the blood collection, you may experience brief pain, discomfort and/or bruising at the site the blood was taken from. Rarely, there could be a minor infection or bleeding. If you have experienced any side effects previously from having blood taken, please tell the blood collector prior to having your blood taken. Should you experience any distress or discomfort, support is available from your study doctor.

Health Information (Data): There is a very small risk that a connection to your identity could be made. Great care will be taken to ensure the confidentiality of all data and that the risk of a breach in confidentiality is considered very low. The study is in line with the Data Protection Act (2018) and GDPR (2016/679).

11. How will I find out what happens with this research study?

If you wish, the researcher will inform you of your test result by telephone. If you wish to be informed of your test results, please indicate on your consent form. This is not a screening test for Q fever, a positive result means that you have antibodies to Q fever in your blood which may be a result of past infection. If you are concerned or develop symptoms, please contact your GP.

Any results obtained from the study may be reported in medical/scientific journals and disclosed at medical/scientific conferences. No information that reveals your identity will be disclosed.

Data Protection

12. What information about me will be used in this research study?

UCD CVERA will use the following information about you (personal data) for this research study: Name, age category, gender, townland of residence and information about your contact with animals.

UCD CVERA will take a blood sample from you.

13. How will my data be used?

Your data will be entered into a secure database, where it will be combined with the data from other participants in this research study. Your name will be replaced with a unique code when we enter your test results and details (age category, gender, townland, and animal contact) into our database. This means your information won't show who you are. Because it's coded, we can match it back to you if we use the key, whereas truly anonymous data can never be linked back to you.

Storing Your Information Safely: Your personal details will be kept separately in a secure system that only authorized people can access curated by UCD with restricted access to trained study staff.

The blood samples will be transported to the laboratory and analysis will be carried out to measure the level of antibodies to Q fever in your blood. Access to the samples will be granted to researchers trained in this study only.

With your permission, samples may be used for future research into markers of infectious diseases or their treatments, subject to ethical approval. Your name, date of birth or contact details will not be linked to these samples. The only information that will be linked to these samples is your age category, sex, and occupational risk group. Please initial the box on the consent form to indicate that you agree to future research. Samples stored for future research may be stored for 15 years and are then destroyed.

The results of the study will be reported in medical/scientific/educational journals and disclosed at medical/scientific conferences. No information which reveals your identity will be disclosed.

Future Data Handling: After the study, we will remove any details that can identify you. We will keep this summarised, anonymous data securely for 10 years for future research and to help publish our findings.

The UCD Research Ethics Committee Board will review any future research related to the cohort study, including any use of data or stored samples.

14. Who will have access to my personal data? What will happen to my personal data?

Only the principal researchers, Dr Katie Corridan and Professor Conor McAloon will access your identifiable personal data. They will replace your name with a code so that it will not be possible to link this data back to you without the key to the code. The academic research team will access coded data only.

15. How will my personal data be protected? Will it be kept confidential?

Your privacy is important to UCD CVERA. All information which is collected about you during the research will be kept strictly confidential, and any identifiable information about you will be removed from all samples/records/reports so that you cannot be recognised. All your personal data will be labelled with a research study code instead of your name, which will be known only to the researcher. A master list identifying participants with the research codes will be held on a password protected (encrypted) computer accessed only by the researcher. Hardcopy or paper data will be stored in a locked cabinet, within a locked office, accessed only by the researcher. Electronic data will be password protected and accessed only by the researcher. These actions will be taken to protect your personal data.

All the members of the Research Team have taken General Data Protection Regulation (GDPR) training at University College Dublin.

16. How long will my data be retained by this project?

With your permission, samples may be used for future research into markers of infectious diseases or their treatments, subject to ethical approval. Your name, date of birth or contact details will not be linked to these samples. The only information that will be linked to these samples is your age category, sex, and occupational risk group. Please initial the box on the consent form to indicate that you agree to future research. Samples stored for future research may be stored for 15 years and are then destroyed.

Future Data Handling: After the study, we will remove any details that can identify you. We will keep this summarised, anonymous data securely for 10 years for future research and to help publish our findings.

17. What is the lawful basis to use my personal data?

UCD will rely on the legal bases of Article 6.1(a) consent, Article 6.1(e) 'public interest' and we will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations.

19. What are my rights?

You are entitled to:

- object to UCD CVERA's use of your personal data or any further use.

- request access to your personal data and to receive a copy of it (up to the point of anonymisation).
- request inaccurate personal data be corrected or deleted.
- request restriction of UCD CVERA's use of your personal data (if it is inaccurate).
- request deletion of your data, if no longer needed.

By law you can exercise the above rights in relation to your personal data, unless certain limitations apply, for example if the request would make it impossible or very difficult to conduct the research or put the quality of the research findings at risk. For example, if the study results / information has already been published then UCD CVERA will not be able to delete it.

20. Contact details of Principal Investigator, UCD's Data Protection Officer (DPO) and right to lodge a complaint with the supervisory authority (Data Protection Commission)

If you would like to contact a member of the research team for any research-related reason, you can do it via the contact information provided. If any questions are not answered in a satisfactory manner, then contact can be made with a Data Protection Officer at UCD, the details of which are also provided below. Finally, if none of the UCD contacts have given a satisfactory response, details on the Data Protection Commission are provided.

Principal Investigator(s):

Dr Katie Corridan,

Centre for Veterinary Epidemiology and Risk Analysis,

University College Dublin,

Bellfield,

Dublin 4

Katie.corridan@ucd.ie

0858007779

UCD Data Protection Officer: Email gdpr@ucd.ie

Data Protection Commission: https://forms.dataprotection.ie/contact