Q Fever in Ireland:
Characterising Zoonotic Risk

UCD Centre for Veterinary Epidemiology and Risk Analysis and Royal College of Surgeons Ireland

PARTICIPANT INFORMATION LEAFLET (PIL)

1. Introductory statement – Invitation to take part

UCD Centre for Veterinary Epidemiology and Risk Analysis (CVERA) and Royal College of Surgeons Ireland (RCSI) would like to invite you to take part in a research study. This **P**articipant **I**nformation **L**eaflet 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 take your time and 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 and RCSI 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
Belfield
Dublin 4
Katie.corridan@ucd.ie
Phone: 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 people from different areas and 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. This study has been reviewed and approved by the UCD Human Research Ethics Committee.

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 questionnaire answers and blood test results will be kept confidential. Your blood sample will not include your name or any other personal details — instead, it will be linked to a unique study ID number that is assigned to you. All contact details will be deleted once blood results are received by the research team.

If you would like to be informed of your blood test results, we will need to temporarily record your name and contact number so we can send them to you. If you choose to receive your results, you will be contacted by telephone by a member of the research team to confirm your identity and share the result in a secure and confidential manner. After you have received your results, your name and

contact details will be deleted, and your results will only be linked to your study ID number. Your participation is voluntary.

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

Yes, you can change your mind and withdraw from the study at any time, without giving a reason up to the point where your data is anonymised. There are no negative consequences if you decide to withdraw. If you wish to withdraw from this research study, please contact Dr Katie Corridan, (katie.corridan@ucd.ie, 0858007779) who will be able to organise this for you.

While the project will make every effort to delete your data, there are limits to this being possible.

- **If you choose *not* to be informed of your blood test result** (the default option), your name is only recorded on the physical consent form. Following receipt of results of serological study, which is expected in June 2026, the consent forms will be de-identified by removing your name. After this point your data is fully anonymous and we cannot trace it back to you. In this case, it will not be possible to withdraw.

- **If you choose *to be informed* of your blood test result**, your name and contact details are recorded on the physical consent form. We will temporarily link your name and contact details to your unique study ID so that we can notify you. This will be stored separately in an encrypted, access-restricted file maintained by the researcher on a separate server. Following receipt of results of serological study, which is expected in June 2026, the consent forms will be de-identified by removing your name. Once we have informed you of your result, your name and contact details will be securely deleted. After that point, your data becomes fully de-identified, and we will no longer be able to link it back to you. As such, withdrawal of your data is only possible *up to the point* you have received your blood test result.

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. If you would like to withdraw from the study and your data is still identifiable, please contact [Dr Katie Corridan] who can assist you with this.

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 and RCSI 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 the study doctor (katie.corridan@ucd.ie, 0858007779).

Your Health Information (Data):

There is a very small risk that your data could be linked back to your identity. However, this risk is extremely low because of the steps we take to protect your privacy.

- If you do not wish to receive your blood test results (the default option), your personal details (like your name and contact information) will not be linked with your questionnaire or blood sample.
- If you do choose to receive your blood test results, we will temporarily link your name and contact details to your unique study ID, but only until we notify you of your result. After that, your name and contact details will be permanently deleted, and your data will then also be fully de-identified.

All data collected in this study is handled in strict confidence and stored. Anonymised biobank data will be held on secure server in RCSI. We will take every precaution to protect your information and keep the risk of any data breach extremely low.

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

Should you wish to 'opt in' to receive your individual blood test result, the study team will contact you by telephone. Please indicate this choice on your consent form.

Please note that 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 indicate a **past infection**, not an active illness. If you are concerned about your result or develop symptoms, please contact your GP for further advice.

The overall results of the study will be summarised and published in medical or scientific journals and may be presented at conferences. These results will be fully anonymised and will not include any information that could identify you.

In addition, a summary of the final study findings and links to any scientific papers published will be uploaded to our study website: https://www.ucd.ie/cvera/research/qfever_study_info/

This will allow you to see the outcomes of the research even if you choose not to receive your individual result.

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, electoral division 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?

Only the minimum necessary data will be collected and used for the purpose of this study, in line with the principle of data minimisation under GDPR.

Your data will be entered into a secure database and combined with data from other participants in this study. Your name will not be entered in this secure database.

If you **do not** wish to receive your blood test result (the default option), your name and contact details **will not** be linked with your questionnaire or blood sample.

If you choose to receive your blood test result, we will collect your name and contact number and link these to your unique study ID. This linking information will only be kept until you have been informed of your test result, after which your name and contact details will be permanently deleted. At this point, your data becomes fully anonymous.

Data Controllers and Storage:
University College Dublin (UCD) and the Royal College of Surgeons Ireland (RCSI) are joint data controllers for this study. Both institutions are responsible for how your personal data is collected, used, and protected. There is a formal agreement between UCD and RCSI outlining these responsibilities.

Blood Sample Processing:
Your blood samples will be sent to a laboratory at RCSI for processing. Afterwards, they will be sent to a commercial laboratory within the European Economic Area (EEA) for testing to measure antibodies to Q fever in your blood. UCD has a data processing agreement in place with the commercial laboratory to ensure your data is protected. Only researchers involved in this study will have access to your samples. No personal identifiers are sent to the laboratory; only coded sample IDs are provided, ensuring your anonymity is preserved during testing.

Biobank and Future Research:
If you agree, a small portion of your serum sample will be stored securely as frozen samples in a biobank at RCSI for future research into infectious diseases or treatments. This is an optional part of the study and requires your additional consent (please initial the relevant box on the consent form).

The biobank samples will not and cannot be linked to your name, date of birth, or contact details. Instead, only basic information such as your age category, sex, occupational risk group, and electoral division of residence will be stored with the samples. Because these samples are not linked to your personal details, it will not be possible to withdraw your consent for future use of the samples once they are stored.

Any future research using these samples will be subject to ethical approval.

Biobank samples may be stored as frozen serum samples for up to 15 years before they are securely destroyed.

Use of Data and Study Results:
The results of this study will be published in medical and scientific journals and presented at conferences. No information that could identify you will be shared.

After the blood sample results have been recorded, any data that can identify you will be removed. We will keep anonymised, summarised data securely for 10 years to support future research and to publish findings.

Any future research using the stored data or samples will be reviewed and approved by the UCD Research Ethics Committee to ensure your rights and privacy are protected.

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

Your name and (if you choose to be informed of your blood test result) contact details are recorded on the physical consent form. These consent forms are stored in a locked filing cabinet, only accessible to the research team Dr Katie Corridan, Mr Guy McGrath and Professor Conor McAloon. For those who wish to be notified of their blood test result, your name and contact details will be linked to your unique study ID. The linking key (that connects the unique ID to the participant's personal information and contact details if applicable) will be stored separately in an encrypted, access-restricted file maintained by the researcher on a separate server.

Following receipt of results of serological study, which is expected in June 2026, the consent forms will be de-identified by removing your name. For participants who have specifically requested to receive their blood test results, their contact details will be deleted following notification of result.

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 identified. All personal data will be labelled with a research study code instead of your name, which will be known only to the researcher. The linking key (that connects the unique ID to the participant's personal information and contact details

if applicable) will be stored separately in an encrypted, access-restricted file maintained by the researcher on a separate server. Hardcopy or paper data will be stored in a locked cabinet, within a locked office in CVERA, UCD, accessed only by the researcher. Electronic data will be encrypted password protected and accessed only by the research team. For participants that opted in to the biobank storage, RCSI will maintain the anonymised data associated with serum samples on a secure server in RCSI accessible only to the research team.

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

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

Following analysis, the serum samples will be destroyed by the commercial testing laboratory.

For participants who have specifically requested to receive their blood test results, their contact details will be deleted following notification of result. Otherwise, your personal details such as your name will not be linked to your results and your consent forms will be securely shredded following de-identification of the data. Following receipt of results of serological study, which is expected in June 2026, the consent forms will be de-identified by removing your name. We will keep the summarised, anonymous data securely for **10 years** for future research and to help publish our findings.

In addition, and only with your permission, samples may be used for future research into markers of infectious diseases or their treatments, subject to ethical approval. The blood serum is then stored at RCSI's secure bio bank. At this point, all personal data will have been deleted and cannot be linked to these samples. The only information that will be linked is your age category, sex, occupational risk group, and electoral division of residence. Please initial the box on the consent form to indicate that you agree to future research, as this is an opt-in additional consent. Samples stored for future research may be stored for **15 years** and are then destroyed.

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.

18. 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 (up to the point of anonymisation).
- request restriction of UCD CVERA's use of your personal data (if it is inaccurate).
- request deletion of your data, if no longer needed (up to the point of anonymisation).

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.

19. 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.

You have the right to lodge a complaint with the Data Protection Commission if you are concerned about how your personal data is being handled.

Principal Investigator(s): Dr Katie Corridan, Centre for Veterinary Epidemiology and Risk Analysis, Room 008, School of Veterinary Medicine, University College Dublin, Belfield, Dublin 4, D04 W6F6
Katie.corridan@ucd.ie

UCD Data Protection Officer: Email gdpr@ucd.ie

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