



Leeds Institute of Clinical Trials Research

## How we use your data if you collaborate with us

This webpage is relevant to you if you help to design, run, analyse, fund or oversee clinical trials or any other research projects coordinated by the Clinical Trials Research Unit (CTRU), University of Leeds. This includes NHS staff recruiting patients to our trials, staff at other research institutes in the UK and beyond, and staff at commercial companies providing us with services for use in our trials. It also applies if you have requested to use data from CTRU trials for secondary purposes, such as further research.

Please note, this information does not necessarily apply if you are a collaborator who is also taking part in one of our research projects as a research participant (for example if you are being interviewed). If you are doing this, you will be provided with additional details about how your information will be used before you consent to take part.

This information is also not aimed at patients or members of the public who help to design or oversee our studies. If this might apply to you, you can see more about how your information is used here: <https://ctr.u.leeds.ac.uk/privacy-cookies/how-we-use-your-data-if-you-are-a-patient-or-public-contributor/>.

If you or someone else would like this information in a different format, please contact the Quality Assurance department at the CTRU ([medctrug@leeds.ac.uk](mailto:medctrug@leeds.ac.uk)).

We would welcome any feedback you may have on the information presented here. Please get in touch with the CTRU Quality Assurance department at [medctrug@leeds.ac.uk](mailto:medctrug@leeds.ac.uk) if you have any suggestions.

## What information do you hold about me, and how will you use it?

We need to collect some information about you in order to collaborate with you. This will at least include your name, contact details and information about your professional role and employer, provided by you or by a colleague on your behalf when we are due to start working with you. We may also sometimes obtain your details from publicly available sources, for example your employer's website.

We need these details so that we can get in touch with you when required. We will contact you about specific projects that we are collaborating on, about future projects we would like to collaborate with you on, and also about any other matters that are relevant to our ongoing collaboration or relationship.

We may also collect evidence (e.g. your CV or training certificates) to show that your training and qualifications are good enough for you to work on our research. If you have access to any systems that we provide, e.g. database systems such as MACRO/Veridata, then we will also hold your username and passwords related to those systems.

We may also use your personal information to develop research funding applications, to publicise our research projects and the work of the CTRU more generally and to satisfy legal or regulatory requirements applying to insurance, finance and conduct of clinical trials and related research.

All the ways we use your personal information support our research, which we carry out in the public interest. If you have any queries about the way we use your information, or you would like to request that we stop using your data in certain ways, please get in touch with your main contact at CTRU, or with the CTRU Quality Assurance department ([medctrug@leeds.ac.uk](mailto:medctrug@leeds.ac.uk))

In most situations, the University of Leeds has overall responsibility for how your information will be used when you collaborate with the CTRU. The University of Leeds is therefore the 'data controller'. In some cases, this responsibility may be shared with another organisation, or another organisation may be the data controller. Where this is the case, it will be made clear in relevant information about the project or situation concerned. If you would like to find out who is the data controller for data held about you, please get in touch with your main contact at CTRU, or with the CTRU Quality Assurance department ([medctrug@leeds.ac.uk](mailto:medctrug@leeds.ac.uk)).

All the information we have about you will be stored securely on CTRU systems, and we will only ever collect information that we need for specific purposes. All your information will only be accessible to people who need to have access in order to carry out CTRU work. We will not use your information for any other purpose than those described above without first providing more detail about what information would be used, what it would be used for and why.

### **Will you share my information with anyone else?**

We will only share your information for the following reasons:

- Where sharing is necessary for the work we are collaborating with you on (for example, if you are a member of a clinical trial oversight committee, we will need to share your details with other members of the committee to arrange committee meetings)
- Where sharing is required by laws or other research governance (for example, if information is requested by the Medicines and Healthcare products Regulatory Agency, or by a study's sponsor if not University of Leeds)
- Where sharing is reasonable and proportionate to your particular role in collaborating on our work (for example, allowing your details to be shared to help publicise a particular clinical trial or to promote recruitment to the trial)

We will only share your information where there is a good reason for doing so, and we will only share the minimum amount of information needed for specific purposes. If you would like to discuss how we might share (or have shared) your information, please get in touch with your main contact at CTRU, or with the CTRU Quality Assurance department ([medctrug@leeds.ac.uk](mailto:medctrug@leeds.ac.uk)).

### **How long will you keep my information, and what will happen when you no longer need it?**

When you have been involved in working on a clinical trial or other research project, there will be a specific amount of time specified in laws or policies that we need to keep your information for (along with all the other information about the research). This will depend on the project, so you should speak to your main CTRU contact to find out exactly what this means for your information.

We may keep your information for longer than this when we have an ongoing collaboration with you, for example if you might work on further research projects with us. If you would like us to stop holding or using your personal information in this way, please get in touch with your main contact at CTRU, or with the CTRU Quality Assurance department ([medctrug@leeds.ac.uk](mailto:medctrug@leeds.ac.uk)).

In all cases, when we no longer need to hold your personal details, we will securely destroy the information.

## **What are my rights?**

You have the following rights regarding your personal information:

- You can ask us what information we hold about you and ask to have a copy of it.
- You can ask us to correct inaccurate information that we hold about you. It is helpful to us to have accurate information, so we would encourage you to get in touch if you think the information we have about you is not right.
- You can ask us to stop using your information in certain ways if you think the information is inaccurate, not being used correctly or not needed anymore for the purpose we said we needed it.
- You can ask us to stop all uses of your information and delete the information we have about you.

Please get in touch using the contact details below if you would like to act on any of these rights.

You should be aware that there are some limitations to the rights mentioned above. The information we hold about you is being used to support research in the public interest. Research in the public interest has special protection in the law to make sure it is reliable. In some cases, we may not be able to agree to your requests about your information if it would harm the research.

In addition, laws and policies governing clinical trials and other research mean we must keep a record of each trial or project for a period of time after it has finished. This will include your details if you collaborated on one of our trials or projects.

Finally, we will need your contact details in order to collaborate with you on our research. Clearly, you cannot ask us to delete your information while still continuing to collaborate with us.

## **What should I do if I have questions or complaints about how my information is used?**

If you have any questions about how your data is used, or you would like us to amend or delete your details, or access what information we hold about you, we encourage you to speak first with the person or group at CTRU who you are collaborating with, or who has contacted you. They may be able to help or answer your questions. If you do not want to do this, or you have done this and are not happy with the response, please contact the University of Leeds Data Protection Officer (see contact details on this separate page about how CTRU uses data).

If you are not happy with our response to your query or complaint or you feel we are not processing your personal information lawfully, you may contact the Information Commissioner's Office.

For more general information about how data are used at the Leeds Institute of Clinical Trials Research and who to contact in case of a problem, go to <https://ctr.leeds.ac.uk/privacy-cookies/how-we-use-personal-data/>.

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