

How we use information about our patient and public contributors

If you are a patient or public contributor for a clinical trial or research study at the Clinical Trials Research Unit (CTRU) at the University of Leeds, this means we will need to collect and use some information about you. This web page explains this in more detail, and what it means for you. If you might like this information in a different format, contact your main CTRU contact or the CTRU Quality Assurance department (medctrug@leeds.ac.uk).

We hope this page answers any questions you may have. If not, please get in touch with your main CTRU contact first.

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 if you have any suggestions.

What information do we collect about you, and what is it used for?

In order to collaborate with you, we will need to record your **name** and at least one of your **contact details**, depending on your preferences for being contacted (for example, your phone number, postal address or email address). We will use your contact details to contact you about the research studies you are working with. We may also contact you about future studies that we think you might be interested in, or about other information that we feel is relevant to all CTRU's patient and public contributors (for example, to find out about your experiences working with us).

We may have some **information about your health**, for example about health conditions you have or had in the past, or about your accessibility needs, if these are relevant to the work you are doing with us. We will only have this information if you have chosen to share it with us, and we will make sure we treat it carefully and confidentially. You can expect your CTRU contacts to be clear with you about whether any information you disclose will just stay between you, or whether anything would be written down or stored in databases – and you should ask your CTRU contacts to make this clear to you if it is not already.

For some research studies, the research team may ask for some **other information about you**, for example to help find out who are the best people to help with their work. If this is the case, they will tell you about this additional data collection when you start contributing to the project. You may also be asked additional questions about things like your **ethnicity or gender identity** so that we can check we are involving a range of people in our work. It will always be your choice as to whether or not to provide this information to us.

All of our studies offer patient and public contributors some sort of expenses or compensation for the time they give taking part. Usually, this is in the form of a direct bank transfer. We therefore may ask for your **bank details** (if you are happy to give them) alongside some other information to help process and record the payment being made (for example, your **National Insurance number**).

All of these ways that we will use data about you support our research, which we do in the public interest.

Who is collecting my information?

The CTRU is part of the University of Leeds. For most of our research studies, the University of Leeds has overall responsibility for how the information about you is used. This means the University oversees how CTRU uses your information. It also means that if you were not happy about something, you could raise a complaint with the University (see below for more about this).

For some of our research studies, the University of Leeds is jointly responsible with another organisation, or occasionally another organisation has overall responsibility instead of the University of Leeds. Where this is the case, this will be made clear to you when you start contributing to the study.

Will my information be kept secure?

Your information will be kept secure at all times. Because of the nature of the work we do at the CTRU, we have very high standards of security, including for information held physically (such as paper documents) and electronically.

Who will see my information in the research team?

People on the research team that you are in direct contact with through your work on the study will see your name and contact details, unless you have agreed something different with your main CTRU contact. This can include members of the research team outside the CTRU, such as the Chief Investigator of a research study.

Other sorts of information about you will be kept at the University of Leeds and will only be available to people who need access in order to run the study, to provide you with payments for your contributions or to support you or the study in other ways.

Who else will see my information?

In some of our studies, it might be possible that other patient and public contributors would see your name and contact details. Your main CTRU contact will make clear to you whether this is the case, and what choices you have about this, when you start working with us.

If you agree to share your bank details with us so that we can provide you with payments for your contributions, we will share these with the Finance Department within the Faculty of Medicine

and Health at the University of Leeds, as they are responsible for making the payments. The CTRU is also a part of this Faculty.

The Finance department will keep your details for as long as they need to keep a record of the payments they make, in line with University of Leeds policies on data retention (find at more at this website: <https://dataprotection.leeds.ac.uk/>). The Finance department may in some cases be legally bound to share information with other organisations (such as HMRC [Her Majesty's Revenue and Customs]). If this is required, they would only share the information required by law.

Sometimes we need to give other people access to study documents held at the CTRU, for example if we are inspected by the UK medicines regulator, the Medicines and Healthcare products Regulatory Agency, who would look at how we have run the study. The representatives of these and other, similar, organisations are professionally bound to maintain confidentiality of any documents they come into contact with.

There may be other situations for a particular research study where we might share your details. For example if you are an author on a research paper, we would need to share your details with the

scientific journal publisher. We will always be clear about this sort of sharing before we do it, and we wouldn't share your details if you are not happy for us to do it.

Sometimes we share information with other organisations (for example, organisations that fund our work) about the patient and public involvement we do. When we do this, we would never share information in any ways that mean you could be identified. For example, we would usually just share overall numbers of people involved in our studies, or overall numbers of people in terms of characteristics like their age range, ethnicity or gender.

Can I see my information, or ask you to correct it?

You have the right to see what information we hold about you, and to have that information corrected if it is not right. Please get in touch with your main CTRU contact first, if you would like to do these things. We would definitely encourage you to let us know if you are changing your contact details, or if the details we have are not right.

You should also be aware that, although we will do all we can to comply with a request to correct information, there may be some cases where we are unable to amend information that we already

hold. This is because we are legally obliged to keep clear, permanent records of the research we do, so that we can demonstrate that the research was done correctly, to anyone who needs to see this.

How long will my information be stored for?

This will depend on the research study you are working with, and your CTRU contact(s) will tell you how long your details will be held for when you start working with them. Your contact details will be held for as long as we need to contact you about the study, or about other relevant activities (for example, about future studies that we think you might be interested in).

You can ask for us to stop using your contact details at any time, or restrict how we use them – just get in touch with your main CTRU contact to request this. Clearly, if you want us to completely stop using your contact details, then your contributions to any CTRU studies would have to end.

Your details may be recorded on some study documents (for example, meeting minutes) that need to be kept until the end of the study. This includes an additional ‘archiving’ period after the study

when the documents will need to be retained, in case we need to be able to show how the study was run.

Can I ask you to delete data about me, restrict how it is used or object to you using it?

You can ask us to stop any further contact with you at any time, for example if you stop working on one of our studies and don't want any further updates about it. You can also ask us to not send you anything other than information relevant to the study you work on. Get in touch first with your main CTRU contact to request either of these things, if you want to.

You have the right to object to our using your information, and to ask us to delete information we hold about you. If this is what you want to do, we will do what we can to comply with your request. Please be aware, though, that we may be legally obliged to keep some details about you for the duration of the study (including the 'archiving' period after the study) if these details are part of documents that we need to keep in order to show how the study was run. In some cases, it might be possible to remove your identifiable details from these documents, but not always. Please get in touch first with your main CTRU contact if you have any requests along these lines.

What if I have concerns about how my information is being used?

If you have a question or concern about how your information is used, you should first get in touch with your main CTRU contact, as they may be able to advise or reassure you.

If you would still like more information, you should contact the relevant Data Protection Officer. Every organisation has a Data Protection Officer, who is their main contact for anything to do with how your information is used. If the organisation with overall responsibility for how your information is used is not the University of Leeds, then your main CTRU contact will give you details of the relevant Data Protection Officer separately (or you can ask them for this).

For all activities where the University of Leeds is solely or jointly responsible for how your information is used, you can use the following details to contact the Data Protection Officer:

- Email: DPO@leeds.ac.uk
- General Postal Address: University of Leeds, Leeds LS2 9JT, UK

- Postal address for data protection issues: University of Leeds, Room 11.72 EC Stoner Building, Leeds, LS2 9JT
- Telephone number: +44 (0)113 243 1751

If you do contact them, make clear in your message that it relates to the CTRU, and specify which research study it relates to (if relevant).

The University of Leeds data controller registration number provided by the Information Commissioner's Office is Z553814X.

If you are not happy with the Data Protection Officer's response to any queries or complaints, or believe your information is being used incorrectly or unlawfully, you should contact the Information Commissioner's Office if you are based in the UK:

- General website: <https://ico.org.uk/>
- ICO contact webpage: <https://ico.org.uk/global/contact-us>
- Telephone number: 0303 123 1113
- Postal address: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

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