

UKCRC Registered CTU Network Privacy Policy

1. Purpose

The UKCRC Registered CTU Network (hosted by the University of Leeds) is committed to ensuring that any data and information collected and used by the Network are lawful, in accordance to the principles of the General Data Protection Regulation and UK Data Protection Act 2018.

This Policy will help you to understand what data and information we¹ collect and receive, how we process and store data, our security arrangements to keep your data safe, when, and if we share data and information, and how we can ensure your rights are upheld.

This policy covers the services offered by the UKCRC Registered CTU Network which includes its:

- Groups;
- Mailing lists;
- Registration process;
- Newsletter;
- Conferences;
- Workshops;
- Webinars;
- Website.

This Policy does not govern the use of data submitted through any third party website(s) that may be provided as links from the UKCRC Registered CTU Network website.

The University of Leeds hosts the UKCRC Registered CTU Network on behalf of all the Registered Clinical Trial Units. Therefore, for the purposes of GDPR the University of Leeds is the 'data controller', which means it is responsible for how and why personal data are used.

For more information on the University of Leeds Privacy policy please see

http://www.leeds.ac.uk/info/5000/about/237/privacy_notice

We routinely review this policy to ensure it reflects our services and the needs of our members. Any changes to it will be communicated via our website. This policy was last reviewed in February 2019.

¹ Where 'we' is used this refers to the UKCRC Registered CTU Network only and does not include constituent member Clinical Trial Units.

2. What data do we collect and receive?

The UKCRC Registered CTU Network collects data in order to carry out its functions. These include:

- assessing non-commercial Clinical Trial Units against defined criteria for registration;
- helping our member Clinical Trial Units develop and share best practice;
- influencing and responding to regulatory bodies and frameworks; and
- promoting the work of Registered Clinical Trial Units across the UK and Northern Ireland.

The Network collects and processes personal data under a lawful basis of 'legitimate interests' to enable us to carry out and manage effectively the registration process and the services to which our constituent Clinical Trial Units subscribe.

We may request personally identifiable data to enable you to facilitate the registration process and enable you to take advantage of the services offered by the Network such as:

- receiving email updates via a mailing list or directly;
- receiving the Exchange newsletter;
- registering to use the website member resource area (e.g. the Forums);
- becoming a member of an Operational and/or Task & Finish Groups;
- attending workshops, conferences and events; and
- participating in Webinars.

This data may include but not be limited to your:

- full name (first and last);
- e-mail address;
- job title;
- C.V.;
- security prompt questions/answers;
- work address;
- work phone number.

3. How do we use your data?

We use the information you provide to us to operate our services. If you contact us to apply for registration for your Clinical Trials Unit, or to nominate yourself for a Group position or other position/opportunity circulated by the Network then we will use any supporting information you have provided in the clearly outlined process to ensure a fair and rigorous selection process.

We will ensure that we process your information only as necessary to support Network functions.

We may also request or collect information about usage of the Network Website including any messages you post to the Forum message board. When you use the Network website you agree that any such information you provide, including message posts may be stored, and processed by the Network.

Our website uses cookie technology to facilitate ease of website operation. Session based cookies will automatically be deleted when you close your browser and persistent cookies will last until your browser deleted them or they expire. If you do not wish to accept our cookies then you have the option to activate that setting on your browser, however, please note that this may prevent you from accessing certain parts of the Network website and Forum.

We will store your data only for as long as it is required for the legitimate need of the Network service. Data that is collected for a specific process or event will be reviewed and deleted following completion of that process/event. We review annually the data we hold and delete any information that is no longer required.

4. Where are data stored and is it secure?

The information you provide is stored on secure servers. The information is only accessible by Secretariat staff including the Programme Manager, Senior Administrator and Director of the Network. Where data are stored overseas the companies in question have signed up to the EU – US Privacy Shield Framework. This includes Survey Monkey which the Network uses to generate business related surveys and our website which is provided through Yourmembership.com community website providers. YourMembership provide strict security measures to keep all our and your information safe from accidental loss, unauthorised access, disclosure and use. For information on YourMembership security and data please visit: <https://www.yourmembership.com/company/technology/>.

SurveyMonkey acts as a Data Processor in respect of survey responses under the applicable legislation. They may also be a Data Controller in relation to very limited data about responders such as IP addresses. Their Privacy Policy can be viewed here: www.surveymonkey.com/mp/legal/privacy-policy/.

Our mailing lists are provided through JiscMail, which is the national academic mailing list service provided by Jisc. JiscMail acts as the Data Processor under the applicable Data Protection legislation. For details of their Data Protection policy please visit: <https://www.jiscmail.ac.uk/policyandsecurity/index.html>.

From time to time we may also circulate surveys on behalf of other member CTUs or external third party stake holders. The Network is not responsible for how any data is collected,

processed, or stored for any third party surveys circulated. Network members take responsibility for ensuring they understand and agree with third party surveys before agreeing to participate.

Where information is circulated to the International Registration Review Panel for the purposes of reviewing applicant Clinical Trial Units for registration to the Network, the Secretariat will ensure that information is shared securely and deleted by Review Panel members upon completion of the registration process.

Where information is circulated to the Executive Group for the purposes of Sub Group nomination selection, the Secretariat will ensure that the information is shared securely and deleted by Executive Group members upon completion of the selection process.

5. When can we share your data?

The Network does not share your personal information with other organisations or interested parties. Where specific events, workshops or conferences are jointly organised with external third parties; the Network will be required to share any dietary or access information you have volunteered for the purposes of registration/attendance.

6. Links to other sites

The Network communications (emails, newsletters, surveys and social media messages) and the website and Forum may contain links to other external third party websites. The UKCRC Registered CTU Network does not have any control over the privacy or security policy and/or settings of these third party websites. The Network therefore does not accept any responsibility or liability for these websites.

7. Your rights

By law you have the right to:

- Request a copy of the information we hold about you;
- Request that we correct any inaccurate information;
- Request that we delete your information;
- Request the restriction of processing your information;
- Object to the processing of your information

8. Contact us

If you have any specific queries regarding this privacy policy and the security of your information, or you would like to opt out of receiving the Network newsletter 'the Exchange' then please contact the UKCRC Registered CTU Network Secretariat:

Email us regctus@leeds.ac.uk

Write to:

UKCRC Registered CTU Network
Leeds Institute for Clinical Trial Research
Faculty of Medicine
University of Leeds
Worsley Building
Leeds
LS2 9JT

Concerns and contact details

If you have any concerns about the way your personal data is being processed or have a query about the information in this document, please contact the University of Leeds Data Protection Officer using any of the following details:

- 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.

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

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (<https://ico.org.uk/>).