

Orchard OCD Registry Privacy Notice ("Privacy Notice")

1. Who we are

The Orchard Obsessive-Compulsive Disorder (OCD) Registry (the "Registry") is a UK-based service with the aim of matching individuals experiencing OCD who are interested in potential research opportunities ("Volunteers") with researchers conducting studies into OCD.

If you decide to join the Registry, this Privacy Notice provides information on how the University of Hertfordshire and Orchard processes your personal data when you sign up as a Volunteer of the Registry.

The University of Hertfordshire and Orchard are joint Data Controllers for the Registry and references to "we", "us", or "our" in this Privacy Policy are references to the University of Hertfordshire and Orchard collectively.

If you have any questions about this Privacy Notice or our data protection practices, please contact the Data Protection Officer (DPO) using the details as set out in Section 11 below.

2. What information we collect from you

When you sign up to be a Volunteer with the Registry, we will ask for the following information from you through our online registration form:

- Name
- Month and year of birth
- Gender
- Ethnicity
- First part of postcode
- Your history of OCD
- Information about any current treatment you may be receiving (for example type of treatment, duration)
- Whether you have a family history of OCD
- Your preferences with regards to research studies
- Your preferred method of contact

Contact details for your preferred method (for example telephone number, email address).

We collect personal data directly from Volunteers via:

- Completion of the online Registry form upon initial sign up (as well as over the phone if you decide to complete the form this way - see below for data gathered)
- Telephone number - if you ring us to change or update your personal details
- Email - we check in each year to see if Volunteers still want to be part of the Registry and to update any details that may have changed

Once you have registered as a Volunteer, if you need to contact us to update your details or because you have a query, we will request your name and month and year of birth so that we are able to identify you from our database.

3. How we use your personal data

The research studies to which we aim to match Volunteers sometimes have specific criteria for the types of participant they need. For example, a study may want to investigate how effective a new OCD treatment is for individuals who have already received multiple treatments in the past. In this case they will only ask for people who fit this description. By providing the above information, we can match you to studies that you are suitable for instead of asking you to read through all of the study criteria yourself. This should therefore save you time.

In summary, we will only use your personal data for the purpose for which we collected it. These purposes include the following:

- To match you to appropriate research opportunities within the UK
- So that we can contact you if we have any questions about your information, if we want to check with you whether you still want to be a member of the Registry, or otherwise manage your relationship with us.
- To update you on any changes to the Registry that may apply to you.
- To create reports on the number of people in the Registry as well as a summary of demographics (age, gender, ethnicity) of members. Note: No identifiable information (e.g., name or date of birth) will be revealed in these reports.
- To improve the service.

We are entitled to use your data in these ways because:

- The use of your personal data as described is necessary for our legitimate interests; or
- You have provided your prior consent.

4. Special categories of personal data

“Special categories personal data” are subject to specific protection or restriction by law in the UK. For these purposes, “special categories of personal data” relate to: racial or ethnic origin; political opinions; religious or philosophical beliefs; trade union membership; genetic data; biometric data; data concerning health; or data concerning sexual preferences, sex life or sexual orientation. We will only process special categories of personal data if permitted by law and only if one of the following conditions is met:

- the processing is necessary to protect the vital interests of you or another person where you are physically or legally incapable of giving consent;
- the data in question has been made public by you;
- the processing is necessary for reasons of substantial public interest on the basis of local law which is proportionate to the aim pursued and which contains appropriate safeguarding measures;
- the processing is necessary for archiving purposes in the public interest or scientific and historical research purposes or statistical purposes; or
- as otherwise permitted by law; and

In each case we will meet any additional legal requirements and enforce any applicable duties of confidentiality effectively, for example in relation to access to health records.

5. Where your data is processed and stored

Once you complete the Volunteer registration form with your information (or complete the form over the phone with a member of our team), your information is then made available to us. The information you provide is stored on a secure database known as REDCap, which is the responsibility of the University of Hertfordshire.

6. How we protect your data and keep it secure

To keep your data secure, it is stored on a database which is encrypted and kept behind a secure University of Hertfordshire firewall. It will only be accessed by individuals on the Registry team.

7. How long your data is kept for

Your information will be kept for as long as you decide to be part of the Registry. If you decide you no longer want to be a member, you can contact us via email and we will remove your information.

Once a year, we will contact you via email to check if you are still happy to be a Volunteer on the Registry. In this email we ask that you respond saying "YES" if you would like to continue being a Volunteer, and we suggest that you check and edit your details via the link we send to ensure they are up to date. If you decide you would no longer like to be a volunteer, you can respond with "REMOVE MY DATA" to this email and your information will be removed. Please note that you can re-register to become a Volunteer again in future if you wish to do so.

If we do not receive a response within 2 weeks of this email, we will send a reminder email. If we do not receive a response within a week we will send a final reminder, and if there is no response to this after a week your data will be removed and you will no longer be a Volunteer. This is so that your data is not kept without you being aware, for example if you had forgotten you registered to be a Volunteer and changed email address.

8. Who your personal data is shared with

Once you join the Registry as a Volunteer, we share your personal data with the parties set out below for purposes set out in Section 3 above:

- staff working for the Registry conducting administrative duties will be able to access your data.
- researchers for purposes of matching you with the appropriate study on the Registry. We require the researchers to respect the security of your personal data and to treat it in accordance with the law.

9. How to access and update your data

You will be able to access your data to view it or make changes at any time. To access your data, you will be provided a username and password that you enter on our website to "Log in". When you sign up initially, you will be asked for information regarding two-factor authentication should you forget your password. This will be in the form of your telephone number or a memorable word which we will ask you to provide if we need to reset your password for you. Once you are logged in, you will be able to see your data and make changes.

The UK General Data Protection Regulation (UK GDPR) states that a lawful basis is necessary whenever an organisation processes personal data. At the Registry, we require informed consent from you as a Volunteer before we can process your data. This means that we need you to provide either written or verbal consent to say you are happy to have your data processed by us.

In order to become a Volunteer on the Registry, you are required to provide your consent when completing the online registration form on our website. By providing us with your consent, you are agreeing for the Registry to:

- store and use your data to write reports and to send you information for research studies you may be suitable for
- contact you to update your details when needed and to check if you are still interested in being a Volunteer on a yearly basis

You can withdraw your consent at any time by contacting us via email, and we are then required to stop processing your data.

10. Your personal data rights

As a data subject, you have the following rights under UK Data Protection laws and you can exercise your rights by contacting the Data Protection Officer (contact details below):

- the right to obtain information regarding the processing of your personal data and access to the personal data which we hold about you;
- the right to withdraw your consent to our processing of your personal data at any time. Please note, however, that we may still be entitled to process your personal data if we have another legitimate reason (other than consent) for doing so;
- in some circumstances, the right to receive some personal data in a structured, commonly used and machine-readable format and/or request that we transmit those data to a third party where this is technically feasible. Please note that this right only applies to personal data which you have provided to us (and not, for the avoidance of doubt, information we otherwise collect about you or information we obtain about you from other sources);
- the right to request that we rectify your personal data if it is inaccurate or incomplete;
- the right to request that we erase your personal data in certain circumstances. Please note that there may be circumstances where

you ask us to erase your personal data but we are legally entitled to retain it;

- the right to request that we restrict our processing of your personal data in certain circumstances. Again, there may be circumstances where you ask us to restrict our processing of your personal data but we are legally entitled to refuse that request;
- the right to object to our processing of your personal data in certain circumstances. Please note that there may be circumstances where you object to our processing of your personal data but we are legally entitled to continue to process it; and
- the right to lodge a complaint with the UK data protection regulator, the Information Commissioner's Office (<https://ico.org.uk/>), if you think that any of your rights have been infringed by us.

11. Changes to this notice

We may update this Privacy Notice every now and then. Each time a Privacy Notice is updated, there will be a "Last updated" section at the top to indicate from which date this notice became effective. The Privacy Notice is available on our website regularly for any changes that may come into effect.

12. How you can contact us

If you have any questions about this Privacy Notice, or any other questions you can contact us:

E-mail: orchardocdregistry@herts.ac.uk

Data Protection Officer: Abigail Tomlinson, dataprotection@herts.ac.uk