

Orchard OCD Registry Volunteer Guide

What is the Orchard OCD Registry?

A registry is a database where information is stored about people who all have something in common. The Orchard OCD Registry was created to match individuals who are interested in being involved in research studies who have OCD, to researchers who require participants. We aim to collect information from adults with OCD and use it to identify potentially suitable studies for them to participate in.

Which organisations are involved?

The Orchard OCD Registry is a collaboration between Orchard, an OCD charity (<https://www.orchardocd.org/>) and the University of Hertfordshire (www.herts.ac.uk).

Can anyone register?

Only individuals over the age of 18 who have OCD (either diagnosed by a professional or who self-identify as having OCD) are eligible to sign up to the registry.

What are the benefits of registering?

Researchers are continuously trying to find out more information and knowledge in order to support the individuals who experience OCD. Unfortunately, many research trials often can't find enough participants and therefore the results are not completely reliable, or the trial is unable to be conducted at all. By having more people involved in research, we can increase our understanding of OCD to aid the development of new treatments.

What types of studies could I participate in?

A range of studies and trials are advertised on the Orchard OCD Registry. Some may be surveys asking you some questions about your experience

of OCD, some may involve trying a novel drug treatment and some may involve testing out a new talking therapy.

When you complete your registration form, you are able to state which types of studies you are interested in and those you are not. You can also decide if you want to receive emails from us if we think you might be eligible for a study. You are able to change your mind and update your preferences at any time while you are a volunteer, either by signing in on our website or by contacting us and speaking to a member of the registry team who will update your information.

How do I register to be a volunteer?

If you are reading this, you will likely have accessed our online registration form and have been asked to read the Volunteer Guide (this document) and our Privacy Notice. Once you have read both documents, you will be required to read our Terms and Conditions.

If you agree to the Terms and Conditions, you will be able to continue with the registration form. The form will require you to provide information about yourself that will help us to identify you on the database, as well as matching you to potentially suitable research studies. Once the registration form is complete, your data will be transferred to our database, and you become a volunteer on the registry.

What happens once I've registered?

Our database will filter through the information you have provided alongside research studies we are advertising, to see if you are eligible for any of these studies. If you are, you will receive an email with the details of the studies we believe you may be eligible for. This will provide information about what is involved in the study and contact details for the researchers so that you can sign up if you're interested.

How do I register for individual studies?

If you are interested in signing up to a study, you will need to contact the research team using the details that are available in the study advert. The research team will then decide whether or not you are eligible to participate in the study. Once you have contacted the researchers and they have agreed that you are eligible, communication from this point regarding the study will be with them and is not the responsibility of the Orchard OCD Registry.

Will I be suitable for all studies?

Not necessarily. While the studies we advertise are all related to OCD, they will be investigating different things. Therefore, researchers have criteria for the participants they would like to be involved in their study. For example, a study may be investigating how effective a new therapy is for OCD, however they only want to test it on individuals who have already received therapy multiple times before.

Once you have entered your information, we will filter which studies you are likely to be suitable for and provide you with the information.

Will my data be safe?

Your data will be kept secure on a database. Please see the Privacy Notice for more information on how we keep your data safe.

What if I no longer want to be a volunteer?

If you decide you would no longer like to be a volunteer of the registry, you are able to let us know by contacting us directly. You can change your mind at any time and do not need to provide a reason for your withdrawal.

We contact volunteers via email on the anniversary of their sign up to check that they are still happy to be a volunteer and providing the option to update their details if needed, but you can tell us any time before then if you'd like us to remove your contact details from the registry.

Please note that by requesting for your information to be removed from the registry, this does not mean any data or information you provided to individual research studies you may have already participated in will be removed. If you would like to find out about withdrawing your data from a study you have already participated in, please contact the listed researcher for that study.

How can I contact you?

If you have any questions, you can contact us via email:

Email: orchardocdregistry@herts.ac.uk

Thank you for taking the time to read this information.