

# Orchard OCD Registry Researcher 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 adults (aged 18+) who identify as having OCD and are interested in being involved in research studies, with researchers who require participants. We aim to collect information from individuals with OCD and use it to identify potentially suitable studies for them to participate in.

While we are looking for adults with OCD to sign up to the registry, we also need studies for potential participants to sign up for. Therefore, if you are a researcher in the recruitment phase of a study requiring adults with OCD, we would invite you to register your study.

## 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](http://www.herts.ac.uk)).

## What are the benefits of registering my study?

We are aware of how challenging it can be to recruit enough participants for research studies. If your study is accepted onto the registry, it will be advertised to volunteers who may be suitable according to your eligibility criteria. Therefore, your recruitment rates may increase, resulting in a higher chance that you will achieve your desired sample size.

## What types of studies are accepted?

We do not currently have a specific criterion for study type. Studies can be those assessing intervention effectiveness e.g., pharmacological or psychological treatment, surveys or questionnaires, biological tests etc.

However, we do request that studies have been reviewed and approved by an Ethics Committee if we feel that there may be ethical concerns. Please note that we may ask for proof that your study has been approved by an Ethics Committee when you apply, for example an email or letter

from an approved body. We also require you to provide us with a study advert that has been approved by an Ethics Committee.

### **How do I sign my study up to the Registry?**

If you are interested in advertising your study on the Orchard OCD Registry, you will need to complete our “Study Registration Form” which is available on the website (<https://orchardocdregistry.org/>). This form asks for information about the study, such as aims, methods, desired sample size etc. which is then submitted to our review team. They will decide whether the study will be accepted onto the registry based on the number of volunteers we have signed up that may aid in your participation, as well as having the appropriate Ethics Committee approvals in place. If the review team have any further questions, they will contact you via the contact details you have provided.

### **Do I need to have approval from an Ethics Committee prior to completing the registration form?**

No. You are able to complete the form and select that you do not yet have approval from an Ethics Committee. The study will be reviewed for suitability, however it will not be advertised yet until we receive proof of approval. Once you have received approval, please contact us at [orchardocdregistry@herts.ac.uk](mailto:orchardocdregistry@herts.ac.uk) and send us proof of approval (e.g., a letter) along with the approved study advert.

### **How are volunteers made aware of my study once it is accepted?**

If your study is accepted onto the registry, volunteers who fit your study’s eligibility criteria will be emailed your study advert. This process of matching volunteers to studies is done through our databases. If volunteers are interested, they can then contact you directly using the details you provide on your study advert. Once a volunteer contacts you directly to be involved in a study, the registry is no longer involved with recruitment.

If accepted, your study advert will also be listed on the “Participate in research” page of our website (<https://orchardocdregistry.org/studies/>). This is where we list all studies which are currently recruiting, and volunteers can also access this page to browse for studies. If they find a

study they appear eligible for and are interested in participating, they will contact you directly using the details you have provided.

### **Can I update information on my study?**

Yes, you can update your information by contacting us on [orchardocdregistry@herts.ac.uk](mailto:orchardocdregistry@herts.ac.uk) and letting us know what amendments you would like to make.

### **Can I have more than one study on the Registry?**

Yes, as long as studies are accepted by our review team they will be advertised on the Registry. You will need to complete a Study Registration Form and have proof of approval by an Ethics Committee for each study.

### **Am I required to follow any rules or policies while my study is on the Registry?**

Please see our [Terms of Engagement](#) regarding this. These are presented at the beginning of the Study Registration Form, and you are required to agree to them before proceeding with registration.

If your study is accepted following review, you will then be sent a personalised agreement statement that you are required to sign. We ask that you agree to share the results of your study with us once it is complete, so that these can be made available on the website. This will allow individuals with OCD, as well as members of the public, to read research findings therefore increasing education and awareness around OCD.

At the end of your recruitment, we require you to complete an [End of Recruitment Form](#) so that we can see the number of volunteers that were involved at different recruitment points in your study. We will send this to you once you let us know you'd like your study to be removed from the Registry.

### **How do I remove my study from the Registry?**

If you decide that you would no longer like your study to be advertised on the registry, or you have achieved the desired sample size, please contact us at [orchardocdregistry@herts.ac.uk](mailto:orchardocdregistry@herts.ac.uk). We will then update the website so that your study still shows on our "Participate in research" page, however

its status will say “No longer recruiting” and your contact details will be removed so that no further volunteers can contact you.

If you would like your study removed from the website completely, please let us know and we will do this for you.

If you have any further questions, you can contact us via email.

Email: [orchardocdregistry@herts.ac.uk](mailto:orchardocdregistry@herts.ac.uk)

Thank you for taking the time to read this information.