

Tool: Sample Recruitment & Outreach Material

This fact sheet lists frequently asked questions (FAQs) patients commonly have when joining a registry. Use this tool to create and customize your recruitment and outreach materials.

What does your participation in this contact registry mean?

For the purpose of this contact registry, “patient” refers to the person diagnosed with [insert rare disease]. “You” refers to the person completing the survey or form. “You” may be the patient or a family member, caregiver, or legal guardian of the patient.

As part of joining the [insert registry name], you will provide the contact information and possibly other information about the patient. Participation is voluntary, and you may withdraw at any time.

Below we offer more details about what information we are collecting, why we are collecting the information, how it might be used, the possible benefits and risks of joining the registry and more. If you have any questions, please contact the registry, [insert name and contact information].

What is a contact registry?

A contact registry is a database that stores the names and contact information and sometimes additional information (e.g., age, sex, race/ethnicity) about people living with the same rare disease. The registry can be national or international.

What is the purpose of a contact registry?

Contact registries provide a means for researchers to quickly identify people living with the rare disease who are willing to participate in research studies. Researchers who are interested in recruiting people with [insert rare disease] can contact our registry. We will contact the registry participants about the study.

What are the benefits of joining a contact registry?

The benefit of joining a contact registry is to attract researchers who will study [insert rare disease], increase knowledge about signs and symptoms, progression (natural history) of [insert disease], learn more about quality of life, and potentially discover treatment options and a cure.

Who can join the contact registry?

People living with [insert rare disease] can contribute information for the registry.

Patients over the age of 18 (who are fully competent to enter into a legal agreement) are eligible to join the contact registry. Otherwise, the parent or legal guardian must answer the contact registry questions for the patient to join.

Will I be expected to update the information or provide additional information in the future?

The [insert registry name] is most valuable for scientific research when it is kept up to date and you will be asked to update your profile and information. We will send out notifications [insert how often/frequency (e.g., annually, every 6 months)] to remind you. You can also update the information whenever there is a change in contact information. We may also reach out to you if additional information or clarification is needed.

Where will the data be stored?

We value and respect your privacy; therefore, all of the information you provide to the [insert registry name] will be stored in [insert location].

Who will have access to the information in the [insert contact registry]?

The designated registry staff will have access to the information provided in the contact registry. Your information will not be shared with anyone else without your prior written consent, unless otherwise required by law.

What are the risks of registering?

There is minimal risk in taking part in the [insert registry name]. The [insert registry name] includes questions that can be sensitive. You do not have to share any information you do not wish to. Another unlikely risk is potential breaches in the computer system. In the event that there is a breach, all registry participants will be notified.

I want to participate in a clinical trial. If I register, is this guaranteed?

Although one of the main goals of the [insert registry name] is to make it easier for patients to participate in research, there is no guarantee that any patient will be eligible and/or selected for a trial.

When we learn about clinical trials for [insert disease name], we will contact you if you are eligible, based on the information you have provided in the [insert registry name]. Please note that research protocols determine eligibility criteria, and not everyone is able to participant in research studies.

Should I join the contact registry if I am not interested in participating in a clinical trial?

Even though you may not be interested in participating in a clinical trial, you may still want to join the [insert registry name]. We can send you information about new treatment or other disease-related updates.

Can I withdraw if I change my mind?

Because your participation with the [insert registry name] is completely voluntary, you can withdraw at any time. Should you decide to withdrawn, you can simply contact our registry coordinator by emailing [insert name] at [insert email address]. When you contact us, all of your data will be removed from the [insert registry name].

Will it cost me to join or be part of the [insert registry name]?

No. There are no costs associated with joining or being part of the [insert registry name].

Who should I contact if I have any questions?

If you have any questions, please contact the [insert registry name] at [\[contact information \(e.g., email\)\]](#).

If you have questions about the joining the [insert registry name] or about participation in the [insert registry name], please contact the registry at [\[insert contact information \(e.g., email\)\]](#).