What is a clinical registry?
A clinical registry is a computer database that collects information about your health and the care you receive as a patient. Your doctor or hospital may ask you if you want to participate in a registry for your condition or disease. If you agree to participate, some of the information your doctor collects while providing your care will be sent to the registry, added to information on other patients who are similar to you, and then used to help improve the quality of your care as well as the care of other patients, now and in the future.

What does a registry do?
Registries collect information on large numbers of similar patients. This information may include things like:
- a patient’s reasons for seeking care,
- treatments they received, and
- how well they did over time.

Because a registry can collect this kind of information about many patients, your doctor can help you choose treatments that have tended to work well for patients like you. If you have an implant, for example, information from registries may also be used to identify poorly performing implants and can alert your hospital about recalls to those components.

How does a registry work?
There are many types of registries. Some track patients who have a particular disease or condition. Others track the performance of medical devices such as artificial joints. Medical experts use information from the registry to understand how well different approaches to treating a condition work.
How does a registry collect data?

When you agree to participate in a registry, information about your health and the care that you receive is electronically recorded by your physician or their staff, into a secure database that protects your privacy. Registries take data privacy and security protocols very seriously, and follow health privacy rules and regulations to protect your health information.

Another aspect of collecting registry information is in the form of surveys and evaluations directly to you, the patient, asking about your post-procedure experiences; questions about pain, stiffness, and your ability to function. The results are known as patient-reported outcomes and are important additional pieces of information to be included with your medical profile. Therefore, if your physician asks you to complete a short survey about how you are feeling after your appointment or treatment, it is very important that you complete the survey.

Why is it important to participate in a registry?

When you allow your health information to be entered into a registry, your information is used by your doctor and other medical experts to improve the quality and safety of the care you and other patients receive, now and in the future. Information from registries also supports medical education and the certification of physicians and health care professionals such as nurses and physical therapists. In short, registries help patients like you receive the best possible care so that you can live better.

I think I am participating in a registry now. Can I access the information in this registry?

Registries often have websites that explain the work they are doing, provide access to scientific studies that used their data and in some cases provide information to the public on the performance of hospitals or doctors.

For more information, contact: