

Frequently Asked Questions:

What is a Registry?

A registry is a collection of information about individuals, usually focused around a specific diagnosis or condition. Many registries collect information about people who have a specific disease or condition, while others seek participants of varying health status who may be willing to participate in research about a particular disease. Individuals provide information about themselves to these registries on a voluntary basis.

Is there a risk that my personal health information can be disclosed?

Government agencies have strict privacy requirements set by law such as the Health Insurance Portability and Accountability Act (HIPAA). OrthoCarolina and OrthoCarolina Research Institute follow all HIPAA regulations therefore, the likelihood of identifiable personal information being shared is very small.

What benefits will someone receive by being involved in a registry?

Participation in a registry is likely to increase what we know about a specific condition (i.e. regenerative medicine therapies), help health care professionals improve treatment, and allow researchers to design better studies on a particular condition, including development and testing of new treatments.

Who owns data collected in the Registry? Who makes decisions as to how data will be used?

The data collected in a disease registry is stripped of personal information. It belongs to the OrthoCarolina Research Institute, and de-identified information may be shared with other approved health care professionals and researchers in the MSKI (Musculoskeletal Institute). However, personal, identifying information is kept private. This registry has a governing committee (MSKI Executive Committee) that makes decisions about how the data can be used or shared.

Can I withdraw from the registry?

Yes. Registries are free and voluntary; there is no penalty for choosing to withdraw at any point.