NIH National Center for Advancing Translational Sciences

RaDaR: RARE DISEASES REGISTRY PROGRAM

Online resources for patient groups on setting up and managing a successful registry.

What RaDaR offers:

- Information about the different types of registries and the roadmap for building a successful registry.
- Step-by-step guidance on setting up and maintaining quality registries for rare diseases to stimulate research.
- Resources and tools to promote best practices and data sharing from the earliest stages of registry development.

https://registries.ncats.nih.gov

How can RaDaR help?

RaDaR is an educational resource to guide registry owners.

Get Started

- Learn about different types of registries
- Determine if a registry for a rare disease already exists
- Discover the milestones for developing a successful registry

Set Up Your Registry

- Create your registry plan
- Determine who should join your registry
- Develop the right questions to ask
- Decide how to collect and store registry data

Manage Your Registry

- Recruit and engage participants
- Review and clean your registry data
- Promote your registry to researchers
- Review registry goals and plan next steps

Get the information you need!

Visit the RaDaR website:

https://registries.ncats.nih.gov

Share your feedback

RaDaR was developed in partnership with the rare diseases community. Please contact us to share your stories, suggestions, successes, and challenges via our online form:

https://registries.ncats.nih.gov/about-radar/#feedback-form