

PATIENT REGISTRY TRANSPARENCY CHECKLIST FOR PATIENT FOUNDATIONS

INFORMATION TO DISCLOSE ABOUT YOUR REGISTRY PUBLICLY

- Purpose of the registry
- Name of the registry vendor
- What information is collected
- What medical records collected and how
- How patient foundation will use the data
- Frequency and methods of results sharing
- How can data be accessed
- Who approves data access
- Is registry approved by the IRB
- IRB name and contact information
- How is data protected
- Primary contact for the registry

Participants or researchers who are considering working with the registry or donating data are encouraged to ask for these disclosures if they're not provided.



This resource is brought to you by the "Best Data Practices for Rare Disease Patient Foundations and Researchers" Working Group Project

