“IRDiRC Recognized Resources”
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- Label highlighting tools, standards, platforms and guidelines which contribute directly to IRDiRC objectives

- Identification of key resources for research communities to accelerate clinical translation
Goals of “IRDiRC Recognized Resources”

- Quality indicator of tools/standards/platforms/guidelines based on specific criteria
- Public label visible on and by resources
- Fundamental to rare diseases research & development community
- Encourages long-term sustainability of tools/standards/platforms/guidelines
Assessment criteria I

- Within IRDiRC’s focus and mission (mandatory)
- Serves the international community (mandatory)
- Functional and accessible with minimal downtime
- Has development and maintenance team
- Clear terms-of-use and license policies
Assessment criteria II

- Adhesion to ethical and privacy policies and requirements
- Quality control and life cycle management processes
- Financially viable for at least 3 years
- Freely available non-commercial product
- Evidence of core impacts
Application and review process

- Application open to all project leaders wishing to contribute to IRDiRC goals
- Call for proposal launched March 2015
- Submission and application reviews conducted on an ongoing basis
- Peer-reviewed reports submitted for approval by IRDiRC Scientific Committee
“IRDiRC Recognized Resources”

- International Charter of Principles for sharing Bio-Specimens and Data
- Orphanet
- PhenomeCentral
- Orphanet Rare Disease Ontology (ORDO)
- DECIPHER
- TREAT-NMD Advisory Committee for Therapeutics
- GA4GH Framework for Responsible Sharing
- HPO
- ICHPT
- TREAT-NMD Patient Registries
- TREAT-NMD Standard Operating Procedures
- Care and Trial Site Registry
- OMIM