



“IRDIRC Recognized Resources”

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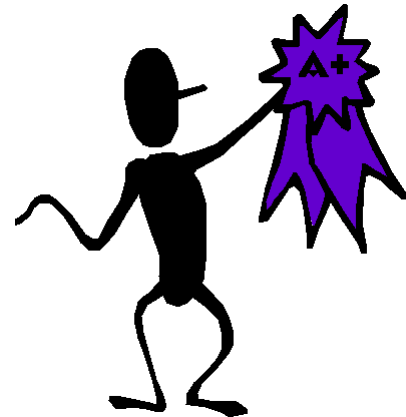
- ▶ Label highlighting tools, standards, platforms and guidelines which contribute directly to IRDiRC objectives
- ▶ Identification of key resources for research communities to accelerate clinical translation

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