IRDiRCs Policies and Guidelines
Principles Applying to Research Activities (I)

- Sharing and collaborative work in RD research
  - Sharing of data and resources
  - Rapid release of data
  - Interoperability and harmonization of data
  - Data in open access databases

- Scientific standards, requirements, regulations in RD research
  - Projects should adhere to IRDiRC standards
  - Develop ontologies and biomarkers
  - Cite use of databases and biobanks in publications
Principles Applying to Research Activities (II)

- Participation by patients and/or their representatives in research
- Act in the best interest of patients
- Involve patients in all aspects of research
- Involve patients in governance of registries
- Involve patients in the design, conduct and analysis of clinical trials
- Acknowledge patients contribution in articles
Principles Applying to Funding Bodies

- Promote the discovery of genes
- Promote the development of therapies
- Fund pre-clinical studies for proof of concept
- Promote harmonization, interoperability, sharing, open access data
- Promote coordination between human and animal models
- Promote active exchanges between stakeholders through information dissemination of ongoing projects and events
Policies and guidelines

Available on www.irdirc.org