



# 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](http://www.irdirc.org)