GOALS OF “IRDiRC RECOMMENDED” LABEL

- Quality indicator of tools/standards/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/guidelines

ASSESSMENT CRITERIA (WHERE APPLICABLE)

- 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 licence policies
- Adhesion to ethical and privacy policies and requirements
- Quality control and life cycle management processes
- Financially viable for at least 3 years post accreditation
- Freely available non-commercial product
- Evidence of core impacts (e.g. number of users/visits)

APPLICATION AND REVIEW PROCESS

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

www.irdirc.org
IRDiRC teams up researchers and organisations investing in rare diseases research to achieve two main objectives:

- Deliver 200 new therapies for rare diseases by 2020
- Develop the means to diagnose most rare diseases by 2020

Members are:

- Funding organisations spending more than 10 million USD over 5 years in research projects contributing to IRDiRC objectives
- Government, academia, industry and patient organisations
OBJECTIVES

- High leverage projects with strong translational potential and international scope
- Targeted action to produce results by 2020
- Projects not covered by international initiatives
- Actionable projects with secured human and financial resources
- Coordination with other organisations to identify gaps and needs
ROLE OF TASK FORCES

MANDATE
▷ Organisation of topic-specific workshops
▷ Production, dissemination and implementation of workshop outcomes

COMPOSITION
▷ Leaders of research projects in the specific fields selected for action
▷ Experts and key players from:
  ▪ Academia
  ▪ Industry
  ▪ Regulatory
  ▪ Advocacy groups

Activity Plan 2015-2016

Q4  Q1  Q2

2015  2016