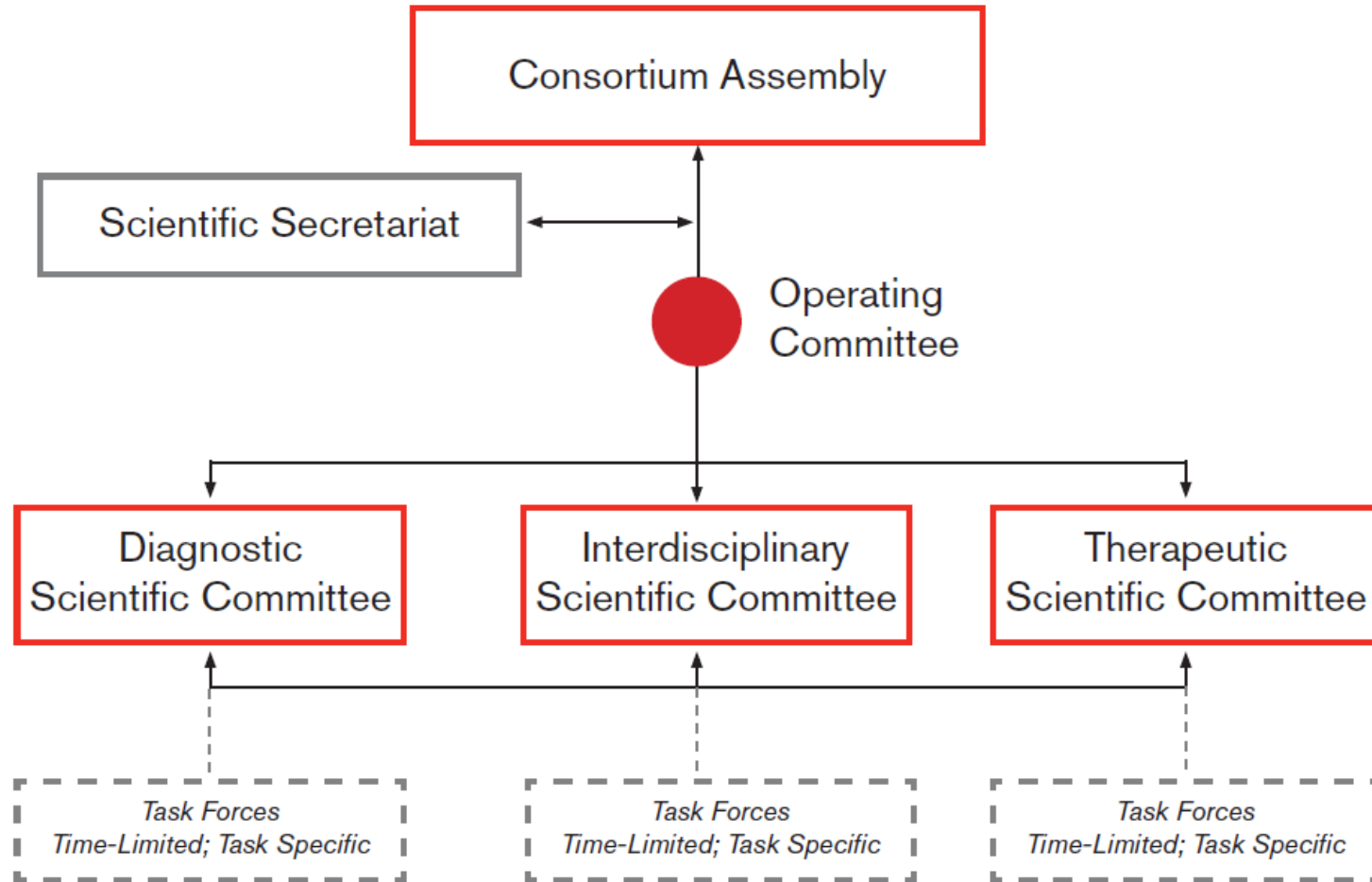




IRDiRCs GOVERNANCE

Governance Structure



Consortium Assembly

▶ Voting members

- ↪ 1 representative per funding body or group of funders
 - Funding agencies, Industry, Research Institutes, Consortium of Funding bodies, Governmental bodies
- ↪ Representatives of patient advocacy groups
- ↪ Chairs of the Scientific Committees

▶ Non-voting members

- ↪ Members of the Scientific Secretariat

Scientific Committees

- ▶ Advising the Executive Committee on research priorities and progress made from a scientific viewpoint
- ▶ ~15 members with balanced representation of scientists, patients, industry, etc.
- ▶ Memberships on nomination basis

Scientific Committees (Sci Comms)

▶ **Diagnostics Committee**

↪ Advises on research related to the diagnoses of rare diseases

▶ **Interdisciplinary Committee**

↪ Provides expertise on cross-cutting aspects of rare diseases research

▶ **Therapies Committee**

↪ Advising on research related to R&D for therapies for rare diseases

Mandate of the Sci Comms

- ▶ Address emerging issues of scientific nature
- ▶ Propose research priorities for consideration by research funding agencies
- ▶ Propose policies and guidelines for adoption by Exec Comm
- ▶ Identify actionable projects and contribute to their implementation
- ▶ Organise the scientific programme of IRDiRC conferences
- ▶ Encourage exchange of protocols and best practices, and agree on standard operating procedures, quality standards, roadmap to reach IRDiRC goals in their scientific area

Scientific Secretariat

- ▶ Based at INSERM US14 – Rare Disease Platform, Paris
- ▶ FP7 contract for 6 years, starting October 2012: “Support IRDiRC”
- ▶ Organisational support to the implementation of the IRDiRC’s roadmap, tracking of IRDiRC goals
- ▶ Management of the website www.irdirc.org and other communication tools

Governance



Available on www.irdirc.org