

Task Force Opening

**Diagnostics Scientific Committee, Interdisciplinary Scientific Committee,
and Funders Constituent Committee**

Primary Care

September 2021

Introduction

The Task Forces are created to tackle specific topics within rare diseases research proposed by the Constituent and/or Scientific Committees and selected as prioritized actions by the Consortium Assembly and the Operating Committee. Each Task Force reviews current barriers to efficient and effective rare disease research and proposes solutions through policy recommendations and/or technical applications including platforms, tools, standards, and guidelines.

Qualities of All Task Force Members:

- ▶ Experts
- ▶ Thinkers and doers
- ▶ Collectively diverse
- ▶ Collaborates well with others to accomplish the objectives of the Task Force
- ▶ Able to commit fairly substantial amount of time to the Task Force in the upcoming year

The usual time commitment includes quarterly 1-hour teleconferences, one face-to-face workshop (1-2 days), and regular email correspondence. Each Task Force will include 1-2 members from the corresponding parent Committee to ensure clear communication and alignment.

Task Force on Primary Care

Objectives:

- ▶ To bring together representatives from the stakeholders required to identify the priority research areas in primary care that need to be addressed to deliver against the IRDiRC goals;
- ▶ To bring together representatives from the stakeholders required to identify current state of play;
- ▶ To identify challenges and opportunities in rare diseases research in primary care. This may include the following area: diagnosis, therapies, ELSI, and patient engagement.

Individuals living with rare diseases typically present first, and often recurrently, to their primary care providers (PCPs). PCPs are therefore central to all aspects of patients' experiences during their rare diseases journey, be it in shortening the diagnostic odyssey, data sharing, access to approved and investigational therapies, care coordination, and social outcomes.

Therefore, this taskforce is critical to all IRDiRC goals and traverses all "IRDiRCians". To realize IRDiRC Goals, especially Goal 1, community-level providers must be engaged.

This Task Force is specifically looking for members with the below qualities and expertise:

- ▶ Primary care health provider with experience/research in rare disease
- ▶ Involvement in strategic planning for rare disease research
- ▶ Able to commit to monthly teleconferences, a yearly meeting, regular committee activities, and email correspondence

Application Procedure

If you are interested in taking part in this IRDiRC activity or would like to propose a candidate(s), please complete the information below and send to the Scientific Secretariat by email at scisec-irdirc@ejprarediseases.org before **29 October 2021**.

- ▶ Name of the candidate
- ▶ Affiliation and location of the candidate
- ▶ Contact information of the candidate
- ▶ Expertise that the candidate is expected to contribute to this Task Force