



**Patient Advisory Council
(PAC)
TERMS OF REFERENCE**





About the Patient Advisory Council (PAC)

The Rare Disease Patient Advisory Council (PAC) will act to inform partners from RD-Connect, EUrenOmics and NeurOmics of issues important to patients. To ensure that all project activities have a patient-centric approach throughout EURORDIS will coordinate activities in relevant projects with the PAC as well as invite its patient representatives to meetings and discussions. Feedback from the PAC will be centralised by EURORDIS and shared with the project coordinators. Two-way communication flow will be promoted by EURORDIS to ensure that recommendations from PAC members are taken into consideration by the relevant leaders of the RD-Connect Work Packages.

As with much research on rare diseases, RD-Connect, EUrenOmics and NeurOmics will navigate new research territory requiring close collaboration of all stakeholders. To support the collaboration of project partners the PAC will also serve as a platform of education. Patient representatives will be informed of scientific issues and progress; and researchers will be informed of patient expectations and experiences.

A joint Rare Disease Patient and Ethics Council (RD-PEC) will work to address issues, concerns or dilemmas brought forth by the PAC as well as all project partners. It will be comprised of a multidisciplinary group of patients, parents, representatives of patients' organisations, clinicians, legal academics, sociologists, scientists and ethicists. An overview can be found in Figure 1.

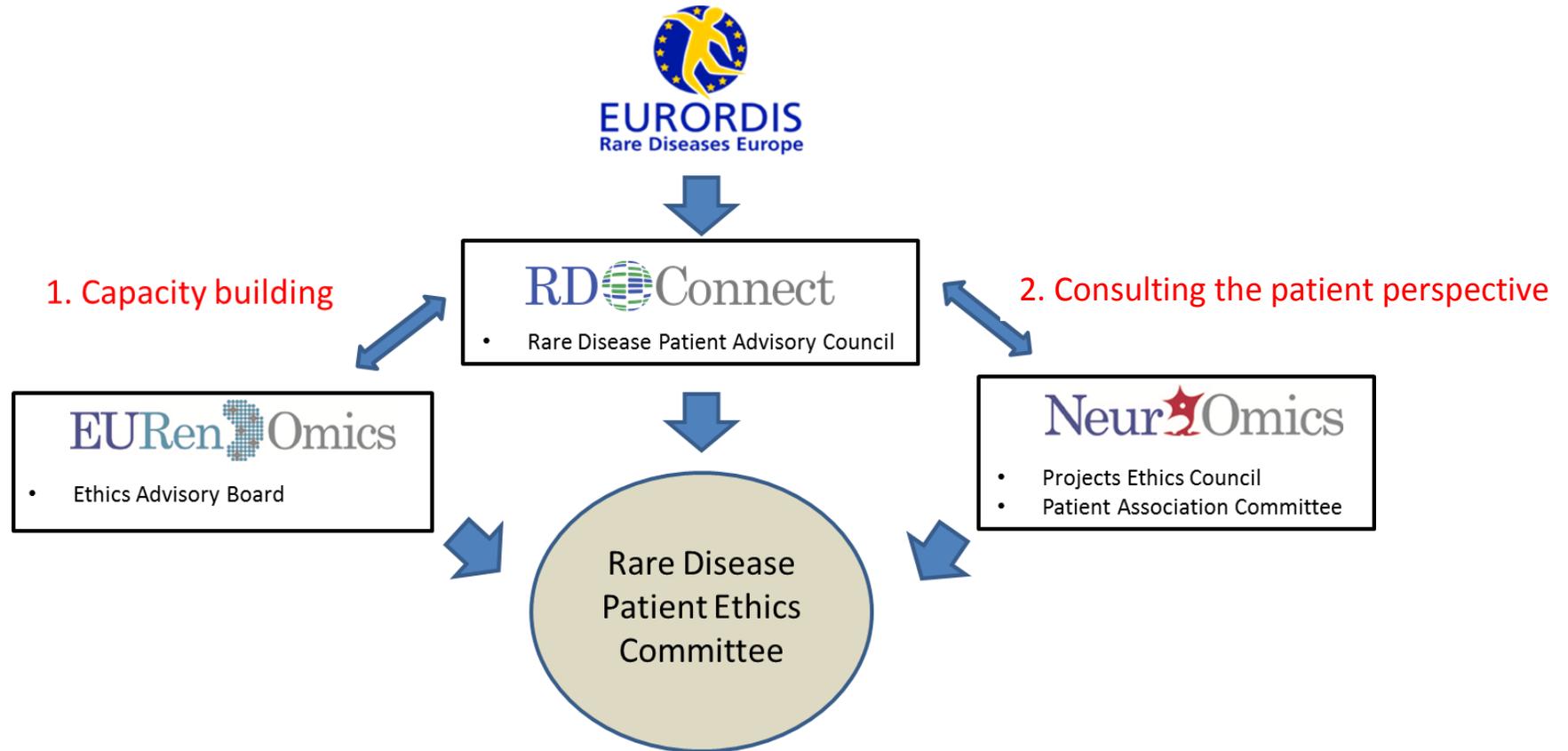


Figure 1. An overview of the role of the Patient Advisory Council (PAC). The PAC has been established to inform project partners of issues important to patients and guarantee a patient-centric approach throughout project activities. A joint Rare Disease Patient and Ethics Council (RD-PEC) will work to address issues, concerns or dilemmas brought forth by the PAC as well as all project partners.



Objectives and responsibilities of the PAC

The PAC will advise the RD-Connect Governing Board and the project coordinator from the patient perspective on a regular basis. Participant's role in the PAC will be to serve as an active member of a EURORDIS working group collecting different patient views on issues surrounding registries, biobanking and –omics research. More specifically they will:

- identify issues important to patients in the context of the project
- learn/educate other patient representatives about technical, legal, ethical and social issues surrounding the approaches included in the projects by attending capacity building workshops (with full financial support for travel and accommodation)
- communicate on the project's progress with patient constituents
- participate in regular meetings and conference calls
- contribute to or reviewing policy documents and reports representing patient views
- participate in and distribute questionnaires to patient constituents
- provide constructive feedback to the RD-Connect Governing Board and the RD-PEC

Structure and membership of the PAC

The PAC will consist of 10-15 patients and patient representatives representing the diversity of diseases covered by RD-Connect, EUrenOmics and NeurOmics projects and beyond and a representative group of EU countries. Membership is voluntary. Patients and representatives with experience in European networking projects, a good understanding of research issues in their field and strong sensitivity to the fact that the project seeks to build research infrastructures for all rare diseases are encouraged to join.

The RD-Connect PAC will be chaired by the RD-Connect project manager at EURORDIS throughout the duration of the project. The RD-Connect project manager and two additional RD-Connect PAC members will represent the PAC on the Joint PEC.

Members are selected by RD-Connect partners participating on Work Package 6 – Ethical, Legal and Social Issues with respect to patient input.



Outputs of the PAC

Through educational workshops and focus groups (alongside existing project events such as EURORDIS Summer School, EUPATI and RD-Connect, EUrenOmics and NeurOmics as well as IRDIRC meetings) members will be provided with information on -omics research and biobanking. Summaries and conclusions of workshops and meetings will be documented.

These activities will also serve to build much needed trust and partnership around these complex subjects. Workshops incorporated into the above projects will i) inform and empower patients to debate issues around -omics, ii) collect data on their concerns and expectations and iii) allow the co-production of knowledge about their priorities for -omics research and biobanks.

Analysis and outcomes of workshops and focus groups will be used to conduct a Delphi method exercise on which of the emergent issues should be prioritised. This will involve gathering subjective-intuitive data from 'expert' patients and patient representatives and in collaboration with EUrenOmics, NeurOmics and possibly future IRDIRC projects.