

19 April 2023

What is the Patient Partnership Framework?

“Patient partnership can be defined as a mutual relationship between all stakeholders, including patients, where input from people living with a rare disease or their carers routinely and formally informs policy reflections and decisions. {...} considering people living with a rare disease and their advocates as equal partners and actors in policy and programme design and evaluation.” Rare2030 Foresight

A framework is defined as the ideas, information and principles that form the structure of an organisation or plan.¹ The ERN patient partnership framework will seek to:

- Define a **common understanding** of patient partnership across the ERNs.
- Guide people in **planning for, conducting and evaluating** patient partnerships in the ERNs.
- Provide a **blueprint** for patient organisations and other stakeholders partnering in healthcare settings.
- Provide **information** for future publications on the topic.

... and capture this in a short document.

¹ <https://dictionary.cambridge.org/dictionary/english/framework>

Why a Patient Partnership Framework?

- Patient representatives and clinicians are increasingly collaborating in the ERNs, but there is a lack of a common practical framework to guide this collaboration.
- The patient partnership framework will help clinicians and patient representatives align their efforts with patients' needs, leading to more patient-centered care and better health outcomes for people living with a rare and complex condition in Europe.
- Agreement upon a common structure will make collaboration easier and more fluid, as the goals and features that enable collaboration are mutually understood and pre-established.

Who is the framework for?

- Patient organisations, representatives and patients involved in the ERNs
- ERN Coordinators
- ERN Project Managers
- Clinical leads involved in the ERNs
- Researchers involved in the ERNs, and
- EURORDIS

With whom is it being developed?

- The framework will be co-developed with ERN patient representatives, clinicians, and project managers as well as EURORDIS.
- A Core Team of 2 ePAG representatives, a clinician, an ERN Project Manager and EURORDIS representative is leading the development.
- Several working groups, workshops and a survey will ensure input and validation from ERN patient representatives, clinicians (incl. ERN Coordinators) and project managers.

METHODOLOGY

