

WORKSHOP GUIDE: PATIENT INVOLVEMENT IN CLINICAL PRACTICE GUIDELINES INFORMATION FOR PARTICIPANTS

This workshop guide is based on the Patient Partnership Framework for the ERNs and the Guide for Patient involvement in the development of clinical practice guidelines & clinical decision support tools, developed by EURORDIS. Please refer to these two documents if you wish to expand the information provided in this factsheet.

The objective of the workshop is to learn or refresh your knowledge about how and when to involve patient representatives and the wider patient community in the development of clinical practice guidelines (CPGs).

To maximise the outcome of the workshop, please read this factsheet before starting.

We hope you enjoy this workshop!

1— DEFINITION OF PATIENT PARTNERSHIP IN THE ERNs

Patient partnership in the ERNs can be defined as a **mutual relationship between patients and health professionals** where input from people living with a rare disease or caring for someone with a rare disease routinely and formally informs the Networks’ collaborative activities and decision-making.

Patient partnership implies considering health professionals and patients involved in the Networks as equal partners in all ERN activities and domains.

2 – GENERAL TECHNIQUES TO PARTNER (ENGAGEMENT APPROACHES)

SHARE

Where health professionals **share easy-to-understand information** with people living with a rare disease, their families, and their representatives, to help manage a given condition, and inform about new treatments, surgical procedures, or any other health-related matter.

CONSULT

Where health professionals **engage with people living with a rare disease**, their families, and their representatives to **consult them** on the health professionals’ perspective on different ERN-related projects, such as their needs throughout the care pathway.

INVOLVE

Where people living with a rare disease or patient representatives **actively participate or collaborate** with health professionals to plan, implement, monitor, and evaluate ERN-related projects and activities. “The last word” lies with the health professionals.

CO-CREATE

Where people living with a rare disease, their families and their representatives and health professionals’ **partner to plan, implement, monitor, and evaluate activities. Decisions are jointly taken.**

3 – WHAT ARE CLINICAL PRACTICE GUIDELINES (CPGs)?

CPGs are statements that support decision making in a specific clinical circumstance typically related to screening, diagnosis, surveillance, treatment, or long-term follow up. They are based on a systematic evaluation of the most up-to-date medical/scientific evidence.

4 – STAGES TO DEVELOP A CLINICAL PRACTICE GUIDELINE AND POSSIBILITIES FOR PATIENT INVOLVEMENT

STAGE 1 PREPARATION



The **preparation stage** is the time to plan and make important decisions, i.e., define your priorities and goals.

The Preparation stage can be broken down into 3 activities:

- 1 – Topic Prioritisation
- 2 –Team Assembly
- 3 –CPG Scoping through the Population, Intervention, Comparison and Outcome (PICO) questions.

STAGE 2 RESEARCH



In the **research stage** a literature search and analysis of the literature is performed to answer the questions defined in the Preparation stage. The Research stage can be simply subdivided into 4 activities:

- 1 –Literature Search
- 2 –Systematic Review
- 3 –Consensus Process
- 4 –Grading Process

STAGE 3 WRITING



The **writing stage** can be described as the point where the Guideline Development Group goes from evidence to recommendations.

The key stages are:

- 1 – Evidence discussion
- 2 –Evidence to decision meeting
- 3 –Developing recommendations

STAGE 4 IMPLEMENT



The **implementation stage** is where a CPG will be published, disseminated, and communicated.

The key stages are:

- 1 – Publication
- 2 –Dissemination & Communication
- 3 –Implementation