WORKSHOP GUIDE: PATIENT INVOLVEMENT IN CLINICAL PRACTICE GUIDELINES

INSTRUCTIONS FOR FACILITATORS

EURORDIS RARE DISEASES EUROPE

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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 the knowledge of participants 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 facilitating this workshop!

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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

STAGE 1 PREPARATION

Preparation

Involve in the prioritisation of topics.

Involve in the CWG & GDG as core members and in capacity building training on guideline methodology and process.

Share the names of clinicians / experts to be invited to be members of the GDG & CWG.

Co-create of the engagement approach to the patient community in the guideline development process.

Involve in set up a PAG including identifying other patient representatives.

Developing the guideline Scope

Co-create the guideline scope.

Involve the PAG in the development of the guideline scope, shaping the clinical questions (PICO) and rating the importance of outcomes from patient perspective.

Consult the wider community on guideline scope and clinical questions.

STAGE 2 RESEARCH

Literature Review

Involve in the GDG to select and screen the publications and identifying important publications to be included in the systematic review.

Involve in reviewing patient experience in published qualitative literature, focus groups, interviews to capture the patient perspective.

Involve in the identification of gaps in evidence and gathering unpublished non-experimental data. Conducting additional research where no qualitative literature exist e.g.: survey.

Share emerging findings with the PAG.

Appraisal & synthesis of evidence

Involve in the discussions on the quality of the evidence and share underlying opinions.
Grade evidence specifically:

- Weigh the benefits and harms, burdens, and cost of a treatment.
- Raise questions about the practicality of a particular treatment approach.
- Consider to what extent the evidence reflects outcome measures that patients and carers consider important.
- Highlight areas where patient preferences and patient choice may need to be acknowledged in the guideline.

STAGE 3 WRITING

Evidence to decision

Involve in the E2D Meeting to take into account the value that patients place on each outcome, when making judgements for each outcome for which there is a desirable effect.

Share patients willing to accept the possibility of adverse effects against a favourable clinical outcome.

Share patients views on the gaps in the evidence as these areas, patients consider important e.g.: pain and discomfort

Involve in in the Delphi process and identifying experts

Writing the guideline

Involve in developing the wording of the recommendations and included as co-authors or noted in the acknowledgements.

Share valuable insight into how the recommendations can work in practice.

Consult on the final draft guideline will ensure that patients will support the implementation of the guideline.

Involve in the peer review panel to review the guideline before publication.

STAGE 4 IMPLEMENT

Communication & Dissemination

Involve in the communication and launch events of the final guideline.

Involve as co-authors of the scientific journal.

Involve in the assessment of the quality of the guideline using AGREE II.

Co-create a plain language summary of the guideline.

Share the final guideline through the Patient Group's network.

Implementation

Consult patient groups locally on the implementation of the guidelines.

Involve in the implementation team to ensure patients are receiving care that is recommended.

Involve in the monitoring the guideline to ensure it is achieving the outcomes.

Consult on research activities that were identified in the final guideline.

BEFORE STARTING THE WORKSHOP (!):

Familiarise yourself with the facilitator's instructions before starting the session. Consider expanding your knowledge on Clinical Practice Guidelines if needed.

If you are planning to use the slides for the presentation, ensure they are adapted, and the projector is prepared accordingly.

Look for support if necessary to contribute to the facilitation of the session effectively.

Print copies of the information for participants for each participant and distribute them accordingly.

Prepare post-it notes and pencils to distribute among the participants.

Order four flipcharts and customise them to represent each stage. Distribute them strategically throughout the room for optimal visibility and accessibility.

5 – INSTRUCTIONS FOR FACILITATION - 90' WORKSHOP

PREPARATION

15'

The facilitator provides a quick explanation of each of the CPGs development stages. Please refer to the information below for each of the stages and to the slide deck (available under request). The facilitator explains the workshop and distributes the one-pager for participants to each person so they can read it, along with some post-it notes to be used during the workshop.

The facilitator gives **5 minutes to all participants to read the information for participants.**

While the participants are reading the information for participants, the facilitator **creates four "corners" in the room**, one for each step, marked with a flipchart featuring the name of the respective step (4 flipcharts with the name of the stage in capital letters - PREPARATION, RESEARCH, WRITING, IMPLEMENT) - this can also be arranged before the workshop starts.

FIRST ROUND

20'

First round starts. The facilitator will inform the participants that they will have 20' for this first round. Each participant selects the stage where he/she believes patient engagement is more relevant. Participants go to the featured corner of the room, according to their selection. Participants who have selected the same stage, come together, and explore and discuss:

1. Who would you involve in this stage (patients and/or patient representatives)

2. What for (think about all possible activities)

3. Using what engagement approach(es) (check the engagement approaches factsheet!)

Each participant will write down their responses and thoughts using post-its and stick them in the flipcharts that correspond to the stages they have chosen. Once they have finished, participants are free to move to another step and make their contribution using post-it notes.

15'

Time to debrief. The facilitator uses the information from the post-its to facilitate the discussion among all the participants. Please refer to the information below if you need further information on how to involve patients in each of the stages.

SECOND ROUND

20'

Second round starts. The facilitator splits participants into teams of 3-6 people - diversity is encouraged. Facilitator will inform the participants that they will have 20' for this second round. The facilitator asks the teams to select 1 or 2 stages that have been "neglected" in Round 1 (i.e., in Round 1 few or no participants have not chosen it as a stage where patient involvement is relevant). For each of the stages, each team will need to reflect on two questions:

Question 1: What activities should normally be undertaken at this stage?

Question 2: How patient involvement can be enhanced at this stage through the different activities?

10'

Time to debrief with the other teams. The facilitator uses the information from the post-its to facilitate the discussion. Please refer to the information below for further information on patient engagement in each of the stages.

10'

To finalise, all the teams will **reflect together on the learnings** from the activity

6 – PROMPTERS FOR A GOOD FACILITATION

STAGE 1 PREPARATION

- How can patient representatives be effectively integrated into the development of the clinical practices guidelines?
- How can the PICO questions reflect the important aspects to the people living with a rare disease?
- Are the priorities and important aspects to people living with a rare condition important in the definition of the guideline topic? How can they be integrated?
- How can patient representatives consult the wider community?

STAGE 2 RESEARCH

- Can additional perspectives from people living with a rare condition enhance the quality of the research?
- What might be the added value of sharing the emerging findings of the systematic review with the patient representatives?

  How can this be done?

STAGE 3 WRITING

- How can patient representatives be involved in the recommendations phase?
- What might be the added value of integrating patient representatives in the review of the draft?

STAGE 4 IMPLEMENT

- What role can play patient representatives in the dissemination of the guidelines?
- How the engagement with patient representatives may help to enhance the implementation plan?
- How can patient representatives consult the wider community on the implementation plan?

GLOSSARY OF TERMS

AGREE II	The Appraisal of Guidelines for Research & Evaluation Instrument is a tool developed to evaluate the methodological quality CPGs.	Back to page
DELPHI	A consensus-building technique based on a series of questionnaire rounds. The responses are aggregated and shared with the group after each round.	Back to page
CPGs	Clinical Practice Guidelines are evidence-based recommendations that establish high-quality patient diagnosis, care, monitoring, treatment and/or follow-up standards.	Back to page
GDG	Guideline Development Group. An extension of the Core Working Group, with a wider representation of experts (including the CWG) who will review and provide feedback on the work produced by the CWG.	Back to page
CWG	Core Working Group. A group of experts that leads the development of the different stages of the clinical practice guidelines.	Back to page
E2D	Evidence to decision	Back to page
ERNs	European Reference Networks are 24 virtual networks launched in 2017 with the aim of improving the health care of people living with rare diseases in Europe.	Back to page
PAG	Patient Advisory Group/ A committee formed by 8-10 (when possible) patient representatives to provide advice on CPG development. The PAG chair should integrate the CDG.	Back to page
PICO	Population, Intervention, Comparison and Outcome is a framework to help clearly determine, define and structure the different aspects of what will be investigated. PICO helps target the right evidence to use in practice.	Back to page