

Workshop Guide: Gathering Patient Feedback from the patient community to develop a model care pathway for [add condition].

Workshop Title: Co-Creating an Ideal Care Pathway – Patient Perspectives

Objective: This workshop aims to gather insights from the patient community about their priorities and expectations to diagnose, treat and manage [add condition]. The feedback will help shape a model care pathway for [condition] that is being developed by [name of ERN].

Duration: 2 hours

Workshop Agenda

1. Welcome and Introduction (10 minutes)

- Introduce the purpose of the workshop.
- Briefly outline the agenda.
- Establish ground rules for a respectful and inclusive discussion.

2. Setting the Scene: Understanding the context for the exercise (20 minutes)

- Explain what a care pathway is and what the difference is with a clinical practice guideline
- Present JARDIN Care pathway methodology
- Based on the information included in the detailed care pathway scope, present the scope for [condition]. Highlight the specific stages of the patient journey, the target population, the outcome measures and the information/evidence that will be used to develop the care pathway. Use individual slides to highlight the parameters that the pathway will include for the different stages.

3. Identifying Patient Priorities (45 minutes)

- Provide a high-level overview of the needs of the patient community in the care pathway for [condition]. - *You may use an existing patient journey or survey results. If there is no reliable source of information, present your own views based on your personal experience. The objective is to kick-start the group discussion. In all cases, please refer to the source.*

- Break into small groups or facilitate a roundtable discussion (depending on the number of people attending the meeting).
- Have participants envision their ideal care experience from diagnosis to ongoing management. - *Adjust depending on the stages covered by the care pathway that is being developed*
- Ask participants to discuss what aspects of care matter most to them at the different stages (e.g., access, communication, coordination, treatment options, emotional support). Some of them could also be cross-cutting priorities across all stages. Organise the discussion per stage, using guiding questions such as:
 - What are the most important needs?
 - What would ideal care look like at that stage?
 - Who should be involved? specialists, primary care, community services, psychologists, patients, family, nurses, social care services, patient organisations...
 - What topics should be covered?
 - What support services are essential?
 - What outcomes are relevant?
 - What is best practice?
- Document ideas and key themes using post-it notes, a flipchart or a digital whiteboard or shared document (you may also use the slide deck template provided by JARDIN WP6).

5. Prioritisation and Consensus Building (30 minutes)

- Review the key themes and solutions identified.
- Ask participants to vote on the most important priorities.
- If there are opposite views in a certain topic, try to find a common ground
- Discuss the rationale behind the top choices.

6. Next Steps and Closing (15 minutes)

- Summarise the key insights gathered.
- Explain how the feedback will be used.
- Thank participants and provide ways to stay engaged in the process.

Workshop Materials

- Flip charts, markers, and sticky notes (for in-person sessions)
- Handouts summarising the care pathway detailed scoping

- Feedback forms for additional input
- Slide deck template provided by JARDIN WP6

Facilitation Tips:

- Foster an open, judgment-free environment.
- Encourage quieter participants to share their perspectives. Don't forget the power of asking questions!
- Keep discussions focused on capturing ideas and feedback for the task at hand: developing a model care pathway.
- If someone gets stuck with one particular aspect, remind them of the objective of the workshop, and that it is important to have as many areas covered as possible. Make sure to capture these remarks in the flipchart (have a space for "additional topics") or in post-its and include them in the meeting report.