



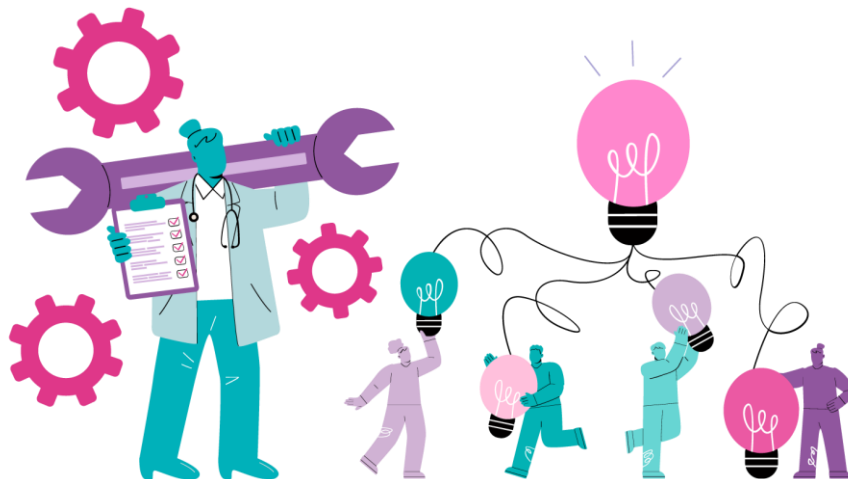
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JARDIN Work Package 6

T6.2 Care Pathway Development Frequently Asked Questions (FAQs)

May 2025



1. WHAT IS THE VALUE OF A CARE PATHWAY WHEN WE ALREADY HAVE CLINICAL PRACTICE GUIDELINES?

Clinical practice guidelines (CPGs) are systematically developed statements that include recommendations, intended to optimise patient care and support clinical decision-making that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options.

Care pathways are tools that translate the recommendations in CPGs into steps to allow them to be operationalised in each healthcare setting. In the 2019 Annex to the ERN BOMS statement on the Integration of ERNs, the development of care pathways is considered a key intervention to ensure: access to specialist care, integration of services, multidisciplinary care co-ordination, standardisation of care across regions and monitoring for constant improvement https://health.ec.europa.eu/document/download/8b07d698-e9bc-4266-a3e2-608eb5d5c91e_en?filename=integration_healthcaresystems_annex_en.pdf

2. IS THERE AN AGREED DEFINITION OF A CARE PATHWAY WITHIN JARDIN?

The agreed JARDIN project care pathway definition is: a methodology for mutual decision making and organisation of care for a group of patients during a well-defined period (European pathway association) using the Lawal AK et al, 2016 operational definition.



3. WHY IS IT BENEFICIAL TO USE THE JARDIN MODEL PROCESS FOR OUR CARE PATHWAY DEVELOPMENT?

The JARDIN Task 6.2 Working Group and the EPAG Care Pathway Task Force co-developed a model process for rare disease care pathway development. This was initially developed by comparing the key activities identified in five published approaches. The consensus agreed model process is presented in a toolkit with tools and resources as a companion to guide healthcare professionals and patient representatives through the development process. T6.2 involves the establishment of around 14 pathway development groups (PDGs) from across the ERNs to pilot the model process and trial the toolkit, tools and resources. Constructive feedback from the PDGs on the utility and usability of the process and toolkit will allow this road test to lead to a refined process and toolkit.

4. IS IT NECESSARY TO HAVE AN APPROVED CPG FOR THIS WORK?

Whilst it is helpful to have a recently ERN-endorsed CPG relevant to the chosen pathway topic and scope of the care pathway, this is not essential. Working from already validated evidence allows the timely development of the care pathway within the timeframe of the project. However, the care pathway development model process includes steps which can be included if evidence is not yet appraised such as; advising the use of AGREE II for guideline appraisal

and a systematic review of the published evidence using GRADE, if required (step 5, page 16 of toolkit). In cases where there are specific gaps in the evidence a Delphi consensus building process may be needed (step 11, page 19 of toolkit). Information sheets on AGREE II, GRADE and Delphi consensus building are also included as resources in the toolkit.

5. IS IT NECESSARY TO CREATE A PATIENT JOURNEY?

The scoping phase of the model process step 7 is the collection of patient needs, experiences and sticking points. A patient journey can be an effective way of capturing patient needs and preferences however it is not a requirement. If a patient journey has already been completed for the selected condition, this can be used as part of the care pathway development process.

Patient Journeys map the common needs of a specific patient community along the different stages of their journey, from first symptoms and diagnosis to treatment and follow-up - identified and described through the eyes of the patients or caregivers (<https://www.eurordis.org/care-pathways/>). On page 17 of the toolkit there are a number of additional tools and resources, which can be used to support the capturing of patients' voices.

6. HOW MANY PEOPLE DO WE NEED TO INCLUDE IN THE CARE PATHWAY DEVELOPMENT GROUP?

The number of people involved in the care pathway development group depends on the scope of the care pathway topic. Representation from each key discipline is recommended. If the condition is multisystemic, this may require representation from a wide number of disciplines. If the pathway scope includes health and social care professionals, representatives from these disciplines can be included. Where possible two lead patient representatives should be members of the core-writing group. Wider stakeholders, for example, hospital managers and patient organisations can also be considered to contribute and review at different stages of the development process e.g. Step 12 final review.

7. WHAT LEVEL OF DETAIL SHOULD WE INCLUDE IN THE CARE PATHWAY?

Each pathway development group can choose the scope, breadth and granularity/level of detail of the care pathway based on their capacity and availability. You may wish to narrow the scope to a small subset of patients and focus on an aspect where there is already a recently endorsed CPG and a current patient needs assessment e.g. a patient journey. If you have more capacity you may decide to do a life-long care pathway, which includes all patient medical, psychosocial, needs and includes relatives in the case of genetic conditions.

8. WHAT IS THE TIMELINE TO COMPLETE THE FINAL IDEAL CARE PATHWAY?

As this work is part of the JARDIN Joint Action, we appreciate that the timelines are tight. The JARDIN project is a 3-year project, which will end in January 2027. The proposed timeline for care pathway development work is one year from Jan/Feb 2024 - Jan/Feb 2025. We understand this timeline is ambitious, but it can be used as a guide to support the care pathway development teams towards reaching key milestones.

9. WILL THESE CARE PATHWAYS BE IMPLEMENTED?

Implementation of the care pathways is not within the remit of T6.2; this is part of task T6.5. For pathway development groups who wish to pilot their pathway under T6.5, the proposed completion date is October/November 2025.

10. IS THERE A JARDIN CARE PATHWAY TEMPLATE WE CAN USE?

There is no specific JARDIN care pathway template for graphical representation of the care pathways given the diversity of topics and scopes. A suite of care pathways are provided as a resource in the toolkit (p19). A selection of editable templates will be circulated to the care pathway development teams.

11. WHAT SUPPORT WILL BE PROVIDED TO THE PDGs?

After the initial kick-off briefing meetings in January and February 2025, any questions arising can be directed to the JARDIN T6.2 team via the pathway project managers. As we have 14 different pathway development groups, this will help to streamline communication.

The JARDIN T6.2 team will co-ordinate and facilitate three peer-huddle sessions planned for April, June and October 2025 to encourage shared learning and problem solving where pathway development teams can meet online to discuss progress, challenges and solutions. Towards the end of 2025 a final 'lessons learned' session will be scheduled with the aim to capture key learnings, which will support the refining of the model care pathway development process.

Eurordis are providing patient representative support and will be establishing contact points via the lead patient representatives involved and through a Community of Practice network, which will meet regularly across the duration of the project.