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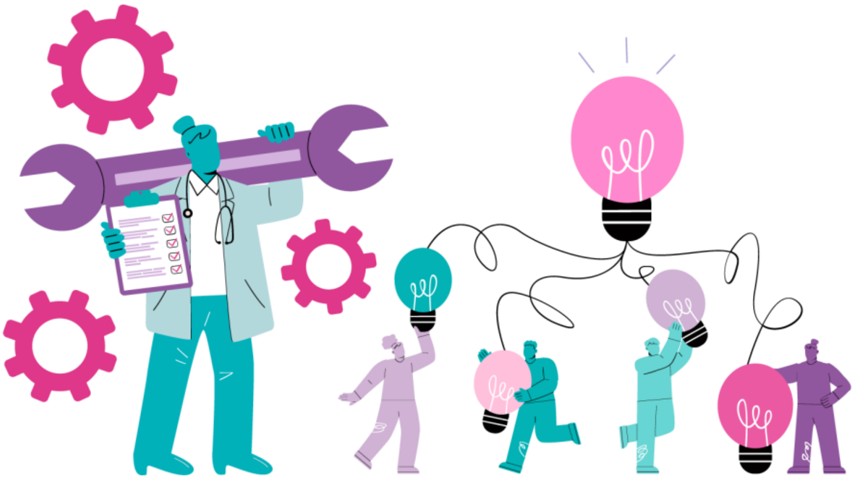
JARDIN Work Package 6

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



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1. WHO WILL BE IN CHARGE OF DEVELOPING THE JARDIN CARE PATHWAYS?

Each ERN should have a project manager dedicated to managing the care pathway development and coordinating its development, alongside a clinical lead and 1-2 patient leads. They will form the Core Writing Group. At different points in time, the Core Writing Group will engage with and seek advice from a larger Care Pathway Development Group integrated by other clinicians and patient representatives (please refer to the toolkit for more details of this governance structure).

2. WHAT IS THE DIFFERENCE BETWEEN CLINICAL PRACTICE GUIDELINES (CPGS), CARE PATHWAYS AND PATIENT JOURNEYS?

Clinical practice guidelines (CPGs) are carefully developed recommendations designed to help healthcare professionals make informed decisions about patient care and treatment. These guidelines are based on thorough reviews of the latest evidence and weigh the benefits and risks of different care and treatment options. Their main purpose is to guide clinical decision-making to improve patient outcomes.

Care Pathways, on the other hand, are tools that translate the recommendations in CPGs into steps to allow them to be operationalised in each healthcare setting. They are structured plans that outline the best way to manage a specific group of patients over a set period. They focus on coordinating care by organising the roles of the care team, defining treatment goals, and ensuring smooth communication between the care team, patients, and families.

Key features which a care pathway may include:

- Clearly defined treatment goals based on medical evidence, best practice and patient needs
- Coordination of care by clearly outlining who does what and when
- Clearly defined roles and responsibilities to improve communication between everyone involved (health professionals, patients, and their families)
- Key performance indicators to track and evaluate patient progress to ensure the best outcomes
- The identification of the appropriate resources to implement the care pathway and improve overall care quality

While **CPGs provide recommendations**, **care pathways put those recommendations into action** by adapting them to specific healthcare settings—such as hospitals, clinics, or long-term care facilities. The goal of care pathways is to improve patient safety, patient experience, and treatment efficiency.

Patient Journeys identify the common needs of a specific patient community along the different stages of their journey through the day-to-day experiences and life-lens of people living with a condition. They are patient-centred documents or tools that map patient community needs and experiences in relation to their clinical presentation at key stages of their care journey. They encompass medical, psychological, and social aspects, highlighting the support required from healthcare and social services to effectively address these needs.

Patient journeys can be harnessed to inform the development of care pathways, ensuring that they are more patient-centred and better meet the needs of individuals (https://www.eurordis.org/care-pathways/).

3. 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.

1. Structured multidisciplinary plan of care
2. Used to translate guidelines or evidence into local structures
3. Details steps in a course of care
4. Aims to standardize care for a specific population

4. 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.

5. 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.

6. HOW CAN WE TRANSLATE THE QUESTIONNAIRE TO CAPTURE THE NEEDS OF MY PATIENT COMMUNITY?

Unfortunately, there is no budget within JARDIN WP6 to support translations. You may use an AI-based translator for the questionnaire and have it reviewed by a native speaker, someone from your patient community, for example. You may use one of these tools to translate the responses too, but the free plans usually support only a limited number of characters (around 5000) - check with your ERN Coordinating team if the ERN has subscribed to a plan with one of these tools that you could use.

7. WHAT IF WE ALREADY HAVE A PATIENT JOURNEY – CAN WE USE IT?

Yes, if you already have a patient journey you can use this or another source that describes the patient community needs in the stages that will be covered by the care pathway.

8. HOW CAN WE USE A PATIENT JOURNEY OR SURVEY PUBLISHED SOME TIME AGO?

You may organise a workshop with your patient community to validate the findings and information that fall within the scope of the care pathway. In this workshop you may also update the information to clarify patient needs, support needed and best clinical practice that might have emerged since the Patient Journey or survey results were published. You may use and adapt the workshop guide and slides available. To avoid collecting information that is not relevant to developing the care pathway, make sure that the workshop focuses on the target population, stages and parameters described in the care pathway scope.

9. 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.

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. On page 17 of the toolkit there are several additional tools and resources, which can be used to support the capturing of patients' voices.

10. 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.

11. 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.

12. 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.

13. 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.

14. 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 is provided as a resource in the toolkit (p19). A selection of editable templates will be circulated to the care pathway development teams.

15. 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.

16. WHAT IS EURORDIS’ ROLE?

EURORDIS Rare Diseases Europe is a unique non-profit alliance of over 1000 Patient Organisations working together to improve the lives of 30 million people living with a rare disease or complex condition in Europe. In the framework of JARDIN, EURORDIS supports patient involvement in the developing of Care Pathways under JARDIN Work Package 6 by providing adequate support, tools and knowledge sharing opportunities to ensure that the care pathway meets the identified patient needs.