JARDIN

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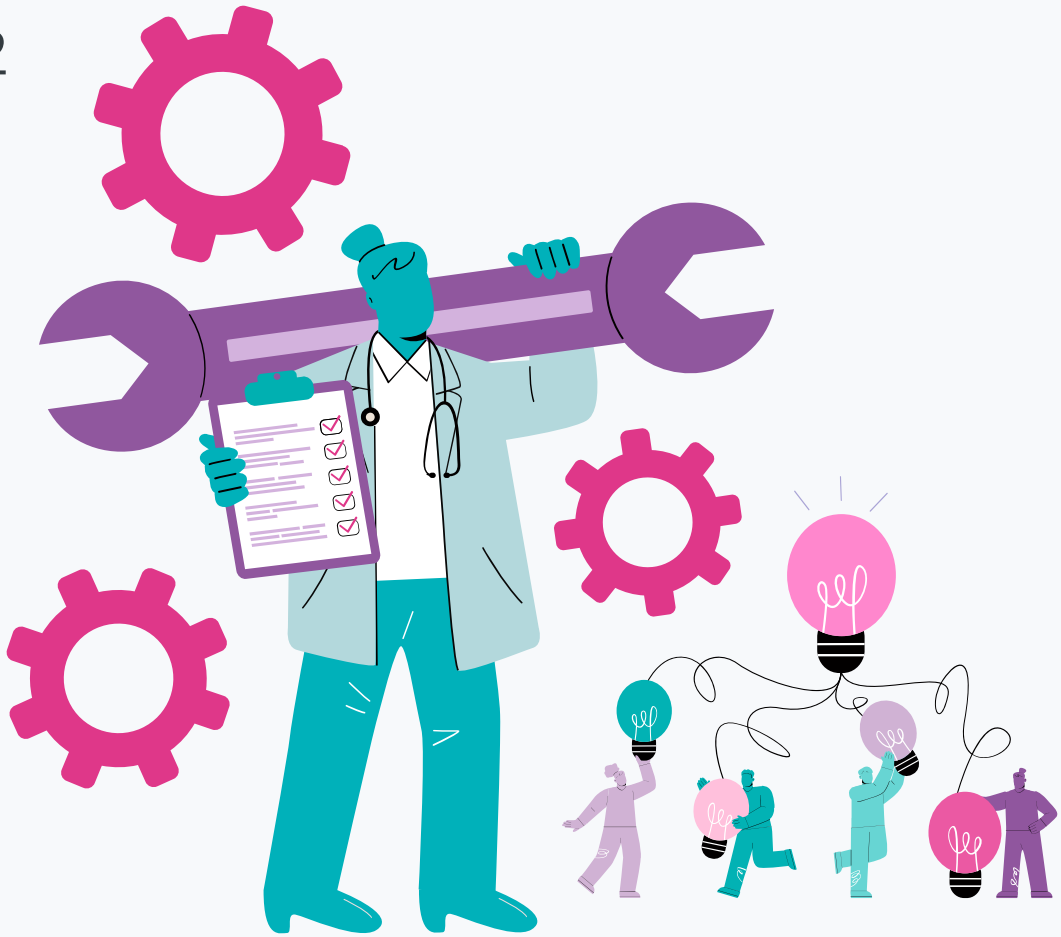
Care Pathways Toolkit for Healthcare Professionals & Patient Representatives

WP6

TASK 6.2



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Care Pathways Toolkit for Healthcare Professionals & Patient Representatives

Final Version 4.4 - 16.01.2025

JARDIN WP6: Task 6.2

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1. Introduction

The majority of rare diseases are complex in nature. To address their multi-systemic needs requires the coordination of care between many specialists across the care continuum, from primary care, community and social services, through to secondary care and specialists in multiple regional and national centres. In health and social care systems, **a 'care pathway' is a tool to enhance the coordination and quality of care across this continuum by improving patient outcomes, promoting patient safety, increasing patient satisfaction, optimising the use of resources** (Vanhaecht K. et al. 2007) and reducing unnecessary variation in best practice and evidence-based care.

These 'care pathways' resemble a detailed care plan, charting each step for a specific patient population to make sure they safely and efficiently reach the best outcomes and quality of life. Care pathways gather in one place all the guidelines and clinical protocols that provide instructions to treating clinicians and relevant professionals across health and social care for delivering optimal care and treatment to patients with specific conditions.

The primary aim of care pathways is to serve as an internal clinical or health management tool that supports the delivery of integrated multi-disciplinary care; enhancing links across acute, primary and community care services; clarifying roles and responsibilities and acting as an educational and clinical support tool. In addition, care pathways are also tools for people with lived experience or those newly diagnosed. They can empower affected individuals to better navigate the health system, increase knowledge and awareness of rare diseases and act as an advocacy tool to support access to both specialist and supportive care.

DEFINITIONS

Whilst the terminology and definition for a 'care pathway' may vary (Lawal AK et al. 2016) within the JARDIN project the T6.2 working group has agreed the definition in line with the BOMS Statement on Integration of ERNs into Member States (2019): 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.

The fundamental purpose of a care pathway is to outline how the needs of a patient group should be best met in the health system. They can vary in detail but aim to enhance safety, optimise resource usage, ensure evidence-based care, and maximise patient satisfaction and outcomes.

Care Pathways are multi-professional, summarise existing guidelines, and detail what happens, when, and who is responsible at each stage. They serve as a reference for everyone involved in care delivery. However, care pathways can often fall short of meeting the complex needs of people living with a rare condition due to the scarcity of knowledge and data available for many rare conditions, which can leave significant gaps in clinical guidelines.

Patient Journeys vs Care Pathways

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. These needs are identified and described through the eyes of the patients or caregivers (Bolz-Johnson et al. 2019). They can be used to map the procedures and treatments documented in a Care Pathway against the needs captured in a Patient Journey, and to identify whether this mapping reveals any gaps in the delivery of care. In this sense, Patient Journeys are a tool to enable patient partnership in the design of care pathways to prioritise activities and resources in the organisation of care services.

Patient Involvement in the Design of Care Pathways

The lived experience of people who use health services is considered an important indicator of quality and survival (Hsee et al. 2012). Therefore, involving 'patients', caregivers and their families in the development of guidelines and care pathways has been recognised as an essential component to organise health and social services that are tailored to the specific needs of the patient populations (Bombard et al. 2018; Doherty C. et al. 2017; Coulter A. et al. 2014; Baker G.R., et al. 2018).

The experience of people living with a health condition is the foundation for building a care pathway. Speaking directly to those with lived experience and creating evidence from their shared experiences and needs provides a stronger picture of the realities they face in accessing appropriate and timely care and treatment.

As the 'end-users' of care pathways, they play a critical role in co-creating the solutions and designing the 'ideal' pathway. In addition, patient representatives play a fundamental role in influencing and supporting the delivery of the system, by creating a case for change with key decision-makers (ref webinar).

European Reference Networks Model (Reference) Pathways

The European Reference Networks (ERNs) are required to exchange, gather and disseminate knowledge, evidence and expertise within and outside the Network, to promote expertise and support healthcare providers in order to bring the local, regional and national provision of healthcare closer to patients. A core activity of the ERNs is to develop and implement clinical guidelines and care pathways.

In their first 5-year cycle, ERNs focused on the establishment of Networks and developing their 'core' services, including the development and adoption of guidelines and clinical decision support tools. Now the ERNs are starting to turn these into 'model reference pathways' and are building referral pathways that bridge from grass-root health services into the Networks.

About the Joint Action on JARDIN: Integrating ERNs into National Health Systems.

JARDIN was launched at the start of 2024 as a 'Joint Action' to support the coordination of community actions between EU Member States, focusing on the integration of the ERN system into national health systems. In October 2017, the ERN Board of Member States (BoMS) established a Working Group on Integration of the ERNs and issued a statement on 25 June 2019 that encouraged Member States to facilitate the integration of ERNs into their healthcare systems by implementing five recommendations, including "creating appropriate patient pathways in order to improve the care and management of patients with rare or complex diseases" (Annex to the Statement on Integration, 2019) by "building on existing pathways, where possible, and linking them to the ERNs where they have not previously been linked". Member States that have no defined pathways for rare or complex disease patients are encouraged to build these along current best practices and in accordance with the disease-specific pathways being developed by the ERNs (Annex to the Statement on Integration, 2019).

Work Package 6: Task 6.2

Work Package 6: National Care Pathways and ERN referral systems (https://jardin-ern.eu/work-package/national-care-pathways-and-ern-referral-systems/), T6.2 is collaborating with the ERNs in the "development of model (reference) care pathways for identified RDs or groups of RDs using the methodology developed by Ward et al. (OJRD Apr 2022), which takes into account a national, patient-centred perspective, and all health system levels from primary to highly-specialised, (to inter-regional) to cross-border care, with intersectoral collaboration, and a holistic and integrated approach. Specifically, this involves mapping of patients' care trajectories by leveraging the expertise collected from the Networks and patient representatives, to inform the design and development of ERN care pathways. Throughout the 3 years of the Joint Action, JARDIN is planning to support the development of more than 10 pathways, which may be for individual conditions or for a thematic group of conditions.

WP6 will also pilot the implementation of some of these care pathways in several Member States. The outcome will be the development of a guide with recommendations for Member States to use to support the implementation of the ERN pathways developed under the Joint Action, as well as future pathways as a deliverable under Task 6.4.

2. What is the purpose of this Toolkit?

This Toolkit has been created to support healthcare professionals, managers and patient representatives in the co-design and development of the ERN care pathways being supported in the JARDIN Joint Action.

EURORDIS and the ERNs are actively working with the JARDIN Joint Action to develop and pilot the implementation of ERN care pathways and to empower patients to inform the design of care pathways based on their own lived experiences.

This Toolkit serves as a "companion" for using the new JARDIN care pathway tools and templates. As such, it details the key steps and methodology required to support the development of high-quality documents that are a collaborative consensus of evidence-based clinical practice guidelines, current clinical practice and capture the patient population priorities and needs.

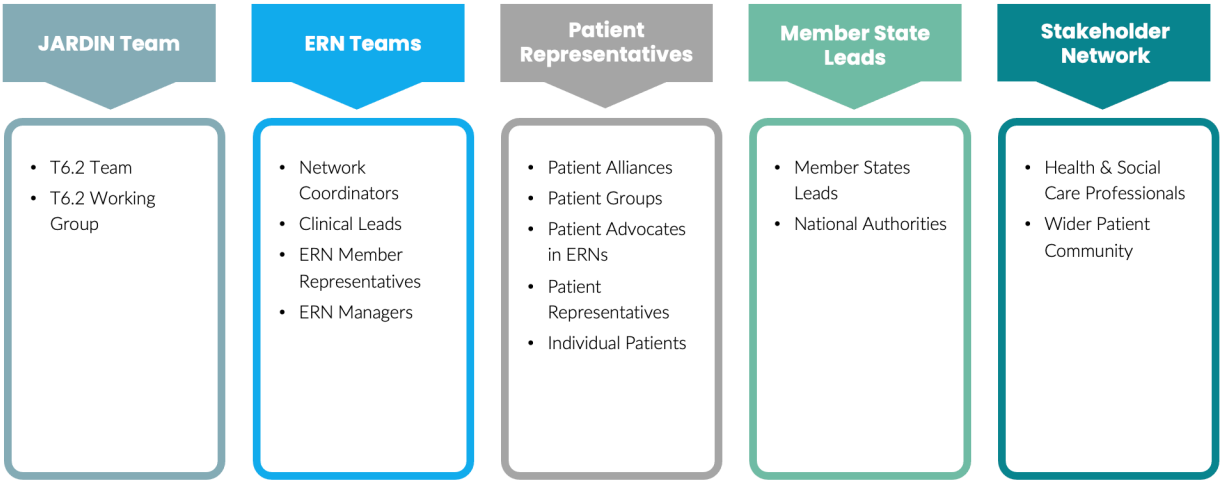
3. Structure of the Toolkit

This toolkit is organised around the Preparation (1), Scoping (2) and Development (3) Phases that coordinate the development of a care pathway. The Implementation (4) and Evaluation (5) phases for care pathways are outside the scope of this toolkit.

The toolkit provides a 'Step-by-Step Guide' which outlines the steps, actions, outputs, roles and responsibilities with key resources such as tools, best-practices and tips to support healthcare professionals and the rare disease patient community engagement throughout this process.

The Step-by-Step Guide is set out in Section 7 of this document. The guide is oriented toward the development of a single condition care pathway, but also provides advice and tips for adapting the methodology for multi-systemic conditions or for thematic grouping of conditions.

4. Roles and Responsibilities



JARDIN Team:

The Joint Action will support the overall development of care pathways across the ERNs but will not specifically support individual-ERN pathways. The T6.2 Working Group will coordinate and provide a common methodology and supportive tools that can be used by each of the ERNs and Health Authorities to develop and implement the care pathways. Please note, the T6.2 Team will not provide management for individual-ERN pathways. However, during the care pathway development process the T6.2 Team will provide initial support on the use of the toolkit and facilitate opportunities for ongoing peer learning and support.

ERN Teams:

The ERNs will coordinate the development of their respective care pathways using the common methodology and tools developed by WP6 Team. ERN Coordinators will identify a Clinical Lead to lead the development of the selected ERN care pathway topic and provide clinical expertise and oversight. A pathway Project Manager will be assigned by the ERNs for each care pathway to develop and deliver a project work plan. They will work closely with the Clinical Lead and ERN Co-ordinator to identify clinical expert stakeholders from the key relevant clinical and health and social care professional disciplines and develop a governance structure.

Patients Representatives:

Rare conditions have different prevalence rates, which results in the rare disease patient populations being a diverse community. Some communities have the critical mass to warrant single disease national patient groups and international federations, whilst other (ultra) rare conditions have small family patient groups or individuals living with a condition collaborating on an informal basis but not supported by a patient group. This diversity in the rare disease community calls for a flexible model of engagement and involvement that can be adapted to the different capacities and needs of each community.

In addition, the majority of rare conditions are complex, affecting multiple body systems. Therefore, developing a care pathway requires involving patient representatives who can be active across multiple ERNs.

- **Patient Alliances** support the overall development of care pathways but do not specifically support individual condition specific pathways by liaising with individual patient groups; they serve as an information hub for sharing information and expertise.

- **Patient Advocates active in the ERNs / ePAG Leads** will provide advice on topic prioritisation for pathways, and the identification of experts, key stakeholders and patient representatives to be involved in pathway development.

- **Patient Groups** will provide lived experience experts to be involved in the individual condition specific pathways and the thematic grouping of conditions pathways.

- **Patient Representatives** are active in the scoping and development phase aimed at mapping common experiences and needs and will be involved in designing the pathways. They do not represent their individual experience but are connected to patient organisations with networks of people who share similar lived experiences for specific conditions. Patient Representatives can be patients themselves and/or caregivers, parents and family members.

- **Individual Patients** can be involved in the scoping and development of a care pathway by being connected to and supported by umbrella patient groups and/or supported by the ePAG Groups

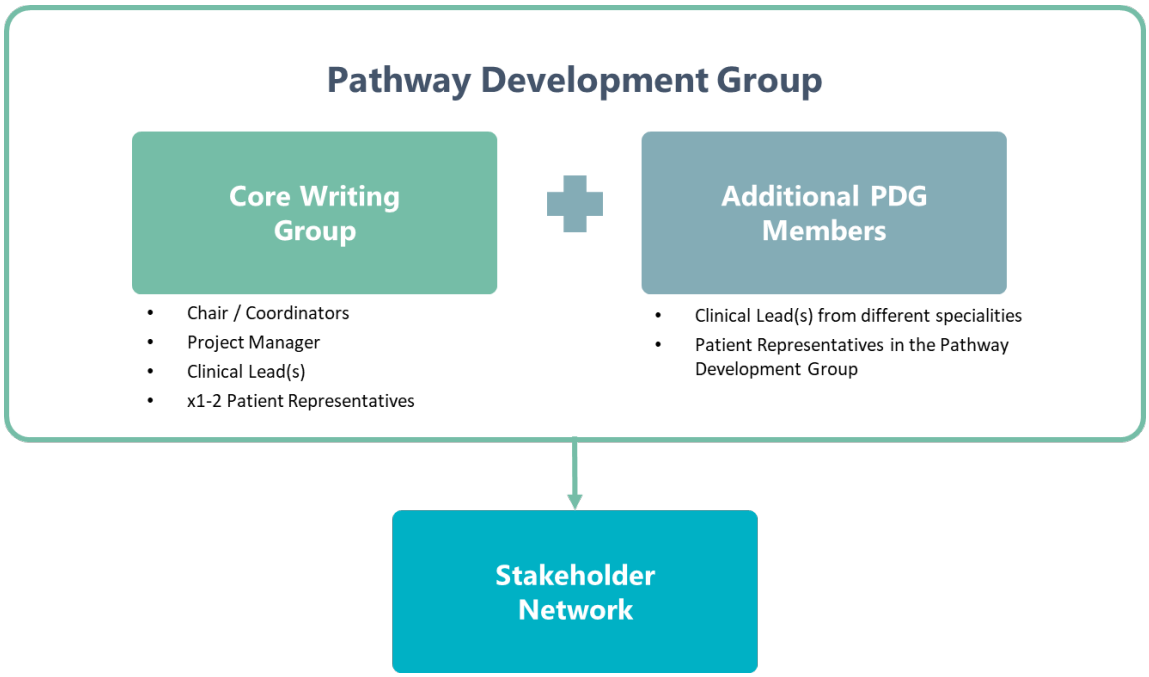
Member State Leads:

The National Authority / Member State Leads will be involved in strengthening the ERN care pathway development model process and methodology and in translating this into local healthcare systems. In addition, they will pilot some of the ERN care pathways in a number of EU Member States and inform the recommendations for Member States to implement ERN care pathways.

Stakeholder Network:

Wider stakeholders may be involved during the care pathway development process including members of the wider patient community, policy makers, hospital managers and health and social care professionals e.g.: physiotherapy, occupational therapy, speech and language therapy, psychology, social work, disability and rehabilitation services depending on the specific scope of the pathway.

5. Governance Structure



The **governance structure will include a Pathway Development Group (PDG) and a Core Writing Group (CWG)**. The CWG members will be key experts from the PDG.

- **The Core Writing Group** will conduct the research and coordinate the development of the care pathways from the outline pathway scope. The Core Writing Group will consist of clinical expert leads and patient representative and are a sub-group of the Pathway Development Group.
- **The Pathway Development Group** will be engaged by the CWG to develop the outline pathway scope into a 'detailed pathway scope' (under Step 4); will be engaged in the key activities (Steps 4-8); will provide feedback on the ideal care pathway (Step 9); and will take part in building a consensus where there is a gap in the evidence (Step 10).
- **Stakeholder Network** will be established from representatives from the wider key stakeholder community, who can be engaged with throughout the pathway development process including policy makers, hospital managers and patient groups.

6. Care Pathway Methodology

Guideline development has agreed upon international best practice methodology for the appraisal of existing guidelines (AGREE II) and for the development of new guidelines (GRADE). However, for the development of care pathways, there is a 'lack of an agreed-upon definition' and therefore no real worldwide consensus on the terminology has been identified. Indeed, more than 37 primary definitions for care pathways have been identified in the published literature (De Blesser et al. 2006) and various terms have been used to describe care pathways in different health settings (Lawal AK et al. 2016).

The 'model process' used in this toolkit for the development of care pathways is based on a systematic review of the different activities used in existing approaches to developing care pathways, including the following:

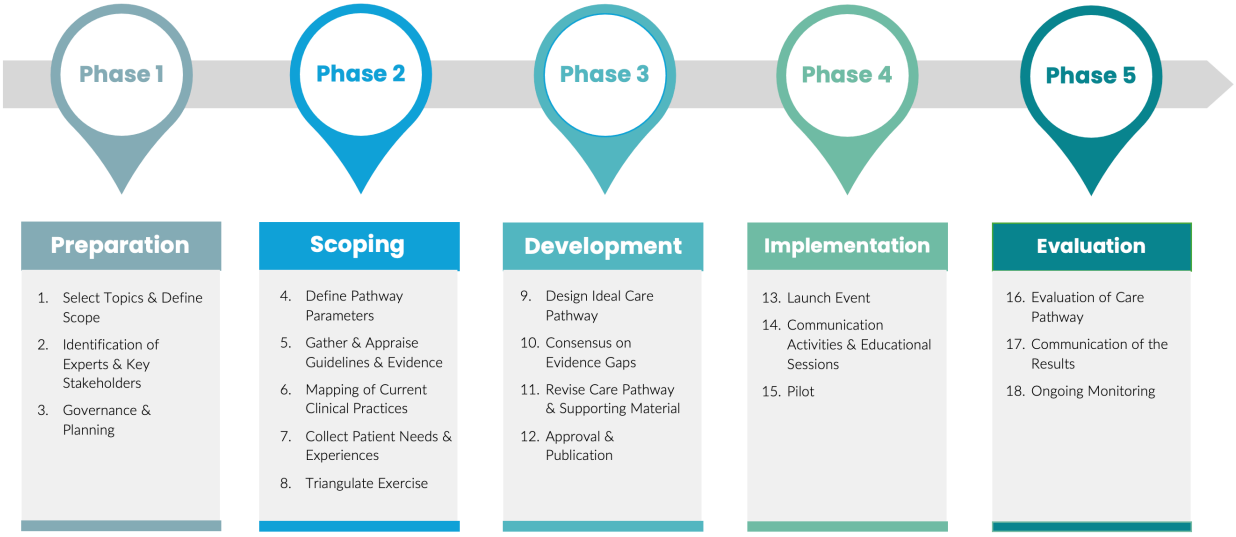
1. European Pathway Association's "Pathway Facilitator Tool"
2. Queensland Health's "Toolkit for the Development of Clinical Pathway"
3. Ireland National Rare Diseases Office's "Co-operative model for developing rare disease care pathways"
4. ERN ReCONNET's "RarERN Path Methodology"

In addition, the methodology was also drawn from the European Reference Networks Clinical Practice Guidelines and Clinical Decision Support Tools, 28 Sept 2020, Aragon Health Sciences Institute, specifically:

5. Handbook 7: Methodology for the development of Diagnostic, Monitoring and Therapeutic Pathways for rare or low -prevalence and complex diseases

7. Overview of the Process

Model Process in 5 Phases



Preparation (Phase 1)

The preparation phase aims to identify potential topic areas (for example, conditions and target populations) for a care pathway to be developed. Once a condition or thematic group of conditions has been selected, the outline scope of the pathway and key disciplinary representation is decided. Experts and key stakeholders are identified and invited to take part in either the 'core writing group' and/or the extended 'pathway development group'. A clinical lead is selected to oversee and lead, and a pathway project manager is appointed to plan and co-ordinate the care pathway development process. The governance structure is established and the planning for the development of the project is completed.

Output: **Project Plan & Outline Pathway Scope**

Scoping (Phase 2)

The Core Writing Group will further detail the pathway scope by including pathway parameters and key outcome measures.

The scoping phase conducts:

- review of existing guidelines and evidence
- mapping of the existing clinical practices is summarised to form a 'baseline pathway'
- capture the shared experiences and needs of the target patient population are used to form a 'patient journey'

The existing guidelines/evidence, baseline pathway and patient journey are triangulated together to identify key bottlenecks and sticking points in the pathway. Feedback is secured from the Pathway Development Group and Key Stakeholders on the findings from the comparison exercise.

Output: **Existing Evidence & Guidelines Repository, Patient Journey & Baseline Pathway**

Development (Phase 3)

Following the triangulation of the evidence-base, baseline pathway and patient journey, the Core Writing Group designs an ideal care pathway. A consensus building exercise is completed where gaps exist in the evidence. Key outcome measures set out in the detailed pathway scope will be used to audit and evaluate the pathway.

Supporting material is developed in parallel. This may include a graphical representation. The final care pathway is peer reviewed and submitted for approval.

The final care pathway and supporting material is signed off by the ERN Network and then published and a communication plan is developed.

Output: **Ideal Care Pathway & Supporting Material**

Implementation (Phase 4)

The first step in implementation of a care pathway at European level is a launch event. This is followed by targeted educational sessions as well as communication activities. At national level, Member States planning to pilot the care pathway will first review the ERN pathway against the existing clinical practice. Once the care pathway has been approved for implementation within a Member State, then the pilot will be conducted.

Output: **Impact Assessment & Launch Event**

Evaluation (Phase 5)

Following the piloting of the care pathway, the utility and effectiveness of the care pathway is evaluated, using the outcome measures that were specified in the scoping phase. The evaluations are analysed, and action is taken to revise the pathway as needed. The results from the evaluation process are communicated to raise awareness around the benefits of the new pathway to encourage roll out in other centres and hospitals. The care pathways should be monitored and updated on an ongoing basis.

Output: **Updated Care Pathway**

8. Breakdown of Steps

The model process for developing a care pathway is broken down into 18 Steps. This toolkit focuses on the first 12 Steps under the first 3 Phases, from Preparation (1), to Scoping (2) and Development (3). The 6 Steps under the Implementation (4) and Evaluation (5) Phases are not included in this toolkit.

Phases	Steps
1. Preparation	1. Select Topics & Define Outline Scope 2. Identification of Experts & Key Stakeholders 3. Governance & Planning
2. Scoping	4. Define Detailed Pathway Scope and Parameters 5. Gather & Appraise Guidelines & Evidence 6. Mapping of Current Clinical Practices 7. Collect Patient Needs & Experiences 8. Triangulate Patient Needs, Baseline Pathway & Published Evidence
3. Development	9. Design Ideal Care Pathway 10. Consensus on Evidence Gaps 11. Revise Care Pathway & Supporting Material 12. Approval & Publication
4. Implementation	13. Launch Event 14. Communication Activities & Educational Sessions 15. Pilot
5. Evaluation	16. Evaluation of Care Pathway 17. Communication of the Results 18. Ongoing Monitoring

9. Step-by-Step Guide

PHASE 1: PREPARATION

STEP 1: SELECT TOPICS & DEFINE OUTLINE SCOPE

DESCRIPTION

Care pathways can be developed for different topic areas such as single rare conditions, multi-systemic rare conditions (e.g., sarcoidosis, neurofibromatosis type 1, etc.), or thematic groups of conditions (e.g., rare and complex epilepsies).

The **WP6 Team in collaboration with the ERN Coordinators, will identify possible care pathway topics that can be developed under the Joint Action,** with the proposal to **develop a minimum of 10 care pathways**. The approved list of care pathway topics will be signed off by the JARDIN WP6 Task 6.2 Working Group.

The critical factor in selecting a care pathway topic is the willingness and capacity of each ERN to identify and engage the Clinical Lead and provide project management support.

Each topic selected for a care pathway will be **developed into an 'outline pathway scope'**. The outline pathway scope will detail the rare condition(s) and target population(s) as well as specify the overall duration of the pathway and care setting.

The Clinical Lead who agrees to lead the development of the care pathway will **engage with the Network Members and Patient Advocates in the ERN**.

OUTPUT: **List of Care Pathway Topics & Outline Pathway Scope(s)**

RESOURCES:

- **Clinician Checklist**
- **Summary factsheet on patient involvement in ERN care pathway development**
- **Example of an Outline Pathway Scope**

STEP 2: IDENTIFICATION OF EXPERTS & KEY STAKEHOLDERS

DESCRIPTION

The ERN Co-ordinator and Clinical Lead, supported by the Pathway Project Manager, will **map the clinical disciplines relevant to the outline pathway scope**, including care coordinators, medical and nursing staff, psychologists, allied health professionals, patients and their representatives, etc. The expert leads representing the main disciplines identified in the outline scope, will be invited to join the pathway development group.

Identify a wider key stakeholder community and their representatives who can be engaged with throughout the pathway development process including policy makers, hospital managers and patient groups.

OUTPUT: **List of Disciplines, Experts & Key Stakeholders**

RESOURCES: **Stakeholder Analysis Planning Tools**

- Stakeholder Analysis and Management Template
- Stakeholder Priority Grid Template

STEP 3: GOVERNANCE & PLANNING

DESCRIPTION

The Clinical Lead and Project Manager will **develop the governance structure and prepare a work plan (including a timeframe)** to coordinate the activities to develop the care pathway (Steps 4-12).

The **governance structure will include a Pathway Development Group (PDG) and a Core Writing Group (CWG)**. The CWG members will be key experts from the PDG.

- **The Core Writing Group** will conduct the research and coordinate the development of the care pathways from the outline pathway scope. The Core Writing Group will consist of patient representative and clinical expert leads from each of the key disciplines required by the pathway scope.
- **The Pathway Development Group** will be engaged by the CWG to develop the outline pathway scope into a 'detailed pathway scope' (under Step 4); will be engaged in the key activities (Steps 4-8); will provide feedback on the ideal care pathway (Step 9); and will take part in building a consensus where there is a gap in the evidence (Step 10).

OUTPUT: **Governance Structure & Project Plan**

RESOURCES: **Project Management Planning Tool**

PHASE 2: SCOPE

STEP 4: DEFINE DETAILED PATHWAY SCOPE & PARAMETERS

DESCRIPTION

The CWG will develop a **detailed pathway scope** including the following **parameters**:

- Patient population(s) – demographics, age range
- Rare condition(s) and sub-types, stage of disease(s)
- Test(s), procedure(s) and treatment(s)
- Stage and duration of the pathway
- Health and social care settings and entry and exit points
- Expected outcome measures including PROMS and PREMS

OUTPUT: **Detailed Pathway Scope including parameters**

RESOURCES: **Example of a 'Detailed Pathway Scope'**

STEP 5: GATHER & APPRAISE GUIDELINES & EVIDENCE

DESCRIPTION

The CWG will **gather and review existing guidelines and pathways** relevant to the agreed scope of the pathway. The PDG (including the patient representatives) can support in gathering and sharing any relevant guidelines, pathways and publications.

Any existing guidelines already endorsed by the ERNs can be utilised, without the need to appraise using AGREE (as this would have already been completed). However, if no approved guideline exists, new guidelines should be appraised in line with international best practice, using AGREE II and a systematic review of the published evidence using GRADE if required.

OUTPUT: **Repository of Evidence & Existing Guidelines & Pathways**

RESOURCES

- **Factsheet on AGREE II Methodology**
- **Factsheet on GRADE Methodology**

STEP 6: MAPPING OF CURRENT CLINICAL PRACTICES

DESCRIPTION

The CWG will engage with the ERN Healthcare Providers (HCP) Members to **gather knowledge and experience from existing care pathways** in their local clinics/departments/centres/hospitals. The CWG can use different approaches to gather real-world experience and knowledge of local clinical practice including workshops, interviews and/or surveys.

The results from ERN HCP Members' centres will be analysed and correlated into a 'baseline pathway' of existing care and clinical practice.

OUTPUT: **Baseline Pathway of Existing Care & Clinical Practice**

RESOURCE: **None**

STEP 7: COLLECT PATIENT NEEDS & EXPERIENCES

DESCRIPTION

The CWG will **collect patient needs, shared experiences and sticking points** faced by the patient population in the selected care pathway.

OUTPUT: **Summary of patient needs and experiences e.g. Patient Journey**

RESOURCES

- **Communication Factsheet**
- **Patient Groups Workshop Slide Deck**
- **Needs Assessment Questionnaire**
- **Patient Journey Guide**
    - **Patient Journey Template 1**
    - **Patient Journey Template 2**
    - **Patient Journey Template 3**
- **Speak Up, Listen Up Toolkit: a survey design e-Toolkit**

STEP 8: TRIANGULATE PATIENT NEEDS, BASELINE PATHWAY & PUBLISHED EVIDENCE

DESCRIPTION

The CWG will **triangulate the published evidence and guidelines** (step 5), **with the baseline pathway** (task 6) **and the patient journey** (step 7), to identify gaps and sticking points in the existing care pathway and main research findings.

The PDG will be **consulted on the results of this comparison exercise**. Following the feedback from the PDG, the CWG will engage key stakeholders (including patient representatives) to secure further feedback on the results from the comparison of the baseline pathway and the patient journey.

OUTPUT: **Summary of the Main Research Findings from the comparison exercise**

RESOURCES: **None**

PHASE 3: DEVELOPMENT

STEP 9: DESIGN IDEAL CARE PATHWAY

DESCRIPTION

The CWG will lead the **drafting of an 'ideal care pathway'** including red flags. The ideal care pathway will be developed based on the main findings and outcome of the triangulation of patient needs, baseline pathways and published evidence (Step 9) and will propose key solutions that address the gaps in the existing pathway.

Draft recommendations will be made throughout the ideal care pathway, supported by the evidence-base and consensus statements. In addition, the CWG should consider the graphical representation of the ideal pathways and also **identify any supporting material** and develop this material in parallel with the development of the ideal care pathway.

OUTPUT: **Ideal Care Pathway, graphical representation & Draft Supporting Material**

RESOURCES:

- **Suite of Care Pathway Template (different formats and graphical versions)**
- **Suite of Care Pathways including Lucid Chart video**

STEP 10: CONSENSUS ON EVIDENCE GAPS

DESCRIPTION

The PDG will be **engaged in a consensus building exercise to address the gaps in evidence** that have been identified in designing the ideal care pathway (Step 11).

The consensus building exercise can be inclusive of experts and leads from the wider community, such as Patient Representatives and other key stakeholders. The selection of experts to contribute to consensus statement development should follow the existing ERN governance structures for seeking expert opinion.

OUTPUT: **Consensus Statement**

RESOURCES: **Factsheet on consensus building methodology (DELPHI)**

STEP 11: REVISE CARE PATHWAY & SUPPORTING MATERIAL

DESCRIPTION

The CWG will **update the ideal care pathway and supporting material, with the outcomes of the consensus building process.**

Once a near-final care pathway is completed, the CWG should review the format of the care pathway presentation and decide on a graphical version of the care pathway.

Key performance indicators (KPIs) including PROMs and PREMs should be developed, based on the outcome measures in the detailed pathway scope. These can be used to audit and evaluate the pathway in Phase 5.

OUTPUT: **Updated Care Pathway (Near-Final Draft), outcome measures / KPIs, graphical representation & Supporting Material**

RESOURCES: **None**

STEP 12: APPROVAL & PUBLICATION

DESCRIPTION

Each ERN Network will define their own internal sign-off **process for quality review and approval in line** with their ERN governance process. However, it is expected that the Final Care Pathway will be peer reviewed within the Network by relevant experts (medical and lived experience experts) who will provide final feedback and make a recommendation for approval by the Network Board.

The Clinical Lead, supported by the Project Manager, will **submit the Final Care Pathway for approval by the Network Board**, or the relevant devolved management group such as the Executive Committee.

The Project Manager will **coordinate the proofreading of the final documents, ready for publication,** as well as obtain quotes for producing a digital version of the final care pathway. The Pathway Project Manager will also **develop a communication plan** based on recommendations made by the CWG and PDG.

The CWG will **draft a publication presenting the final care pathway**. Once approved the Care Pathway will be published on the ERN website along with a peer review publication.

OUTPUT: **Care Pathway (Final), Supporting Publication & Communication Plan**

RESOURCES: **None**

ADDITIONAL INFORMATION

JARDIN will develop recommendations for the implementation of ERN care pathways into EU Member States. It is likely that a quality review by the Multi-Disciplinary Team (MDT) national team and national institute that hosts a Quality Control Body will be a 'gateway' point in the implementation process.

ERNs could include national experts and institutions in the internal peer review process as described in Step 14 to obtain any national feedback before the approval of the Final Care Pathway. Member states can thereby adapt / modify the pathways in accordance with their internal healthcare systems.

10. Resources & Tools

Project Management Planning Tool

A Project Management Planning Tool which includes the key steps of the care pathway development process has been developed for project managers to support co-ordination.

Communication Factsheet

A communication factsheet has been developed for use by Patient Representatives when engaging their respective patient communities. It explains in simple terms the JARDIN project, what a care pathway is and how the rare disease community can contribute to the development of a care pathway. Frequently Asked Questions (FAQ) will be developed as the project evolves.

Workshop Slides

A slide deck template to organise an online or face-to-face workshop to capture needs and ideal support along the care pathway has been developed to support Patient Representatives to engage their patient community to map their common needs and shared experiences. The slide deck includes specific slides that can be used to collect and show results.

Needs Assessment Questionnaire

A Questionnaire has been developed to aid Patient Representatives to capture the needs and views of the patient community. The questionnaire can be delivered through an online survey tool (please contact your ERN care pathway project manager for support if needed). It may also be used in focus groups or as an interview guide to perform in-depth interviews.

EURORDIS **Speak Up, Listen Up Toolkit: a survey design e-Toolkit** is available to help Patient Representatives understand how to best analyse the results from their community (see Step 6 – Analyse your data).

PATIENT JOURNEY

The ERN Patient Journey Templates can be used to present the common needs and shared experiences of the patient community that has been mapped (Step 8) through engaging with their communities. Available templates include (1) Mapping Patient Journey template, (2) General guidance on data collection for patient journeys, (3) Consent Forms, (4) Patient Journey assessment tool, (5) Patient Journey template (Word) and (6) Patient Journey infographic (PowerPoint).

A webinar is also available on “How to develop a Pathway Journey”.

The common needs and shared experiences can be mapped along the different stages of the patient journey, from first symptoms, diagnosis, to treatment and follow-up. These needs and experiences are identified and described through the eyes of the patients and/or caregivers.

STAKEHOLDER ANALYSIS PLANNING TOOLS

The Stakeholder analysis planning tools can be used to identify, understand, prioritise and manage stakeholders involved in the process.

The priority grid can be used to further establish the stakeholder’s level of involvement and impact on the project. Organising stakeholders into each quadrant makes it easy to see who needs the most attention and who can be monitored with less effort. This is a useful tool for strategising and creating an effective plan of action for stakeholder management.

A stakeholder register can assist the team to identify, prioritise, understand and manage stakeholders in a clear and structured approached. By documenting stakeholder management, it reduces the risk of overlooking important elements in this step such as expectations, needs and communication methods.

Appendix I: References

Baker G.R., Judd M., Fancott C., Maika C., & Armstrong P. (2018). Engaging patients in improving health care quality and safety: A systematic review. BMC Health Services Research, 18(1), 581.

Bolz-Johnson M., Meek L., Hoogerbrugge N. 'Patient Journeys': Improving care by patient involvement. European Journal of Human Genetics 28, 141-142 (2020).

Bombard Y., Baker G.R., Orlando E., Fancott C., Bhatia P., Casalino S., Onate K., Denis J.L., Pomey M.P. Engaging patients to improve quality of care: a systematic review. Implementation Science, 2018.

Coulter A., Locock L., & Ziebland S. (2014). Collecting data on patient experience is not enough: they must be used to improve care. BMJ, 348, g2225.

Doherty C., Stavropoulou C., & Saunders M.N. (2017). Patient involvement design of health services quality of care: A systematic review. International Journal of Quality in Health Care, 29(6), 791-795.

European Commission. *Annex to the Statement of the ERN Board of Member States on Integration of the European Reference Networks to the healthcare systems of Member States* (adopted on 25 June 2019).

Hsee L., Devaud M. & Civil I. 2012. Key performance indicators in an acute surgical unit: have we made an impact? World J Surg, 36, 2335-40.

Lawal A.K., Rotter T., Kinsman L., Machotta A., Ronellenfitsch U., Scott S.D., et al. What is a clinical pathway? Refinement of an operational definition to identify clinical pathway studies for a Cochrane systematic review. BMC Medicine. 2016; 14. doi:10.1186/s12916-016-0580-z.

Queensland Health. *Toolkit for Developing a Clinical Pathway*. 2005

Schrijvers G., van Hoorn A., Huiskes N. The care pathway: concepts and theories: an introduction. Int J Integr Care. 2012 Sep 18;12(Spec Ed Integrated Care Pathways):e192. doi: 10.5334/ijic.812. PMID: 23593066; PMCID: PMC3602959.

Vanhaecht K., Bollmann M., Bower K., Gallagher C., Gardini A., Guezo L., et al.L. Int J Integr Care. 2006. Available:.

Vanhaecht K., De Witte K., Sermeus W. (2007). The impact of clinical pathways on the organisation of care processes. PhD dissertation KULeuven, 154pp, Katholieke Universiteit Leuven.

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