

GUIDE TO DEVELOPING A PATIENT JOURNEY



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Introduction

The rare disease community strives to drive improvements in the quality of healthcare services to address the complexity of rare conditions and optimise health outcomes and health related quality of life. Patient involvement in the design and development of clinical services is recognised as an essential component for clinically effective services, in which the organisation of healthcare services is tailored to the specific needs of the patients (Bombard et al. 2018; Doherty C. et al. 2017; Coulter A. et al. 2014; Baker G.R. et al. 2018). This is why patient experience and satisfaction with service quality is considered an important indicator of quality and survival (Hsee et al. 2012).

There are different approaches and tools used to organise healthcare services to best meet the needs of local populations. Population needs assessments and target patient groups can be used to engage and capture patients' needs and real-time insights using different approaches such as health surveys, semi-structured interviews, focus groups and patient journeys. Once the population needs and insights have been mapped, healthcare services can use this information, alongside published evidence and tools, such as care standards, clinical practice guidelines, consensus statements and care pathways, to design and organise care and treatment .

What are Patient Journeys? Patient Journeys are an innovative approach to capture the natural history of a rare condition and the needs of patients through the day-to-day experiences and life-lens of people living with a condition. They offer a patient-driven view of a rare condition, identifying the common unmet needs to address healthcare gaps and enhance health services by concentrating on the patient's daily life perspective.

The Patient Journey approach is a valuable tool to position the needs of people living with a rare condition at the heart of the European Reference Networks (ERNs), guiding the Networks' actions to meet these needs. The approach provides a structured method to patient representatives active in the ERNs to engage with their communities to identify common needs for each rare condition and provides a tool to set these needs out to the Networks. The rich knowledge and lived experience of the patient representatives active in the ERNs can be leveraged to support unlocking the full potential of the Networks to address the needs of patients.



PATIENT JOURNEY VS PATIENT PATHWAY

For the purpose of this guide, it is worth clarifying the difference between the terms “patient journeys” and “patient pathways”.

‘Patient Journeys’ map the common needs of a specific patient community along the different stages of their journey, from first symptoms, 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).

Whereas:

‘Patient Pathways’ are comprehensive and complex plans that guide and support the organisation of care for a well-defined group of patients during a well-defined period (Vanhaecht K. et al. 2006). Patient Pathways gather together in one place the guidelines and clinical protocols that provide instructions to the treating clinicians and relevant professionals across health and social care for delivering optimal care and treatment to patients with specific conditions.

Interestingly, the term ‘Patient Pathway’ is not uniformly used. It may appear as a ‘care pathway’, ‘clinical pathway’, ‘healthcare pathway’, ‘integrated care pathway’, or ‘model pathway’, with each term suggesting a different focus. For instance, a ‘clinical pathway’ typically refers to the care process in a specific clinic or hospital department, whereas a ‘patient pathway’ might describe a patient group’s broader experience through the health system, from initial presentation through diagnosis, treatment, and follow-up. A ‘model pathway’ usually signifies an ideal blueprint for care and treatment that is specific to a defined patient population.

While these types of Patient Pathways may overlap, their fundamental purpose is to outline how the needs of patients with specific conditions should be best addressed in the health system. They vary in detail but aim to enhance safety, optimise resource usage, ensure evidence-based care, and maximise patient satisfaction and outcomes (Vanhaecht K. et al, 2007). These pathways are multi-professional and summarise existing guidelines, detailing what happens, when, and who is responsible at each stage. They serve as a reference for everyone involved in care delivery.

The Patient Journey offers a straightforward approach to improve the quality of healthcare services by making visible the needs and experiences of patients and/or caregivers who have become experts through their lived experience. Patient Journeys can serve to identify and fill the gaps in care pathways for rare conditions, as well as they can also be used for other purposes, for example, to ensure that clinical guidelines are developed to meet patients’ specific and diverse needs and experiences, from symptom onset to follow-up.

Patient Journeys can be harnessed to support structured discussions between patient representatives, clinicians, hospital managers and/or health and social care authorities, specifically to ensure that clinical and care pathways are designed and implemented to meet the underlying needs of the respective patient populations.

What is the purpose of this Guide?

This Guide has been created to support the patient representatives active in the ERNs to develop a Patient Journey for their respective rare conditions.

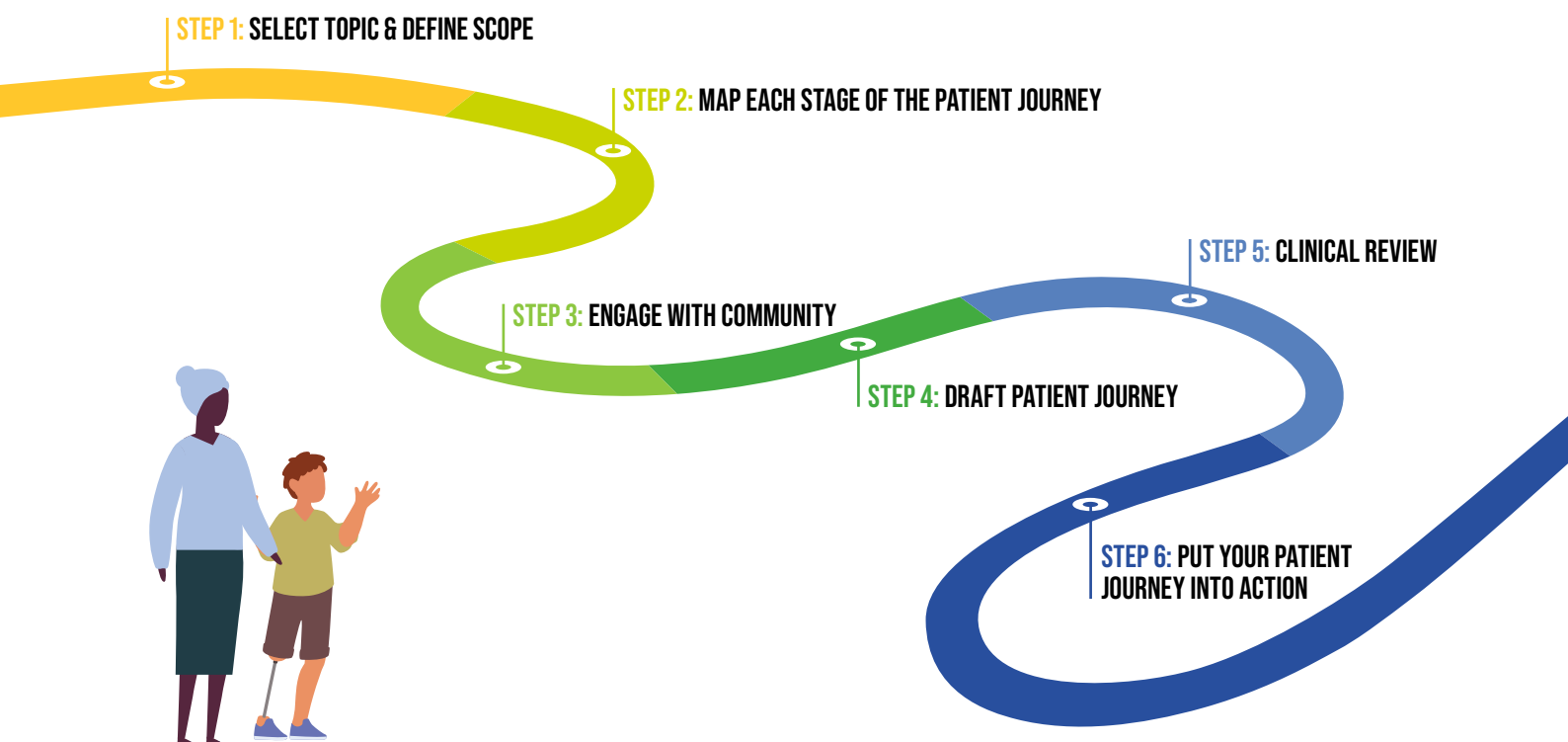
EURORDIS and the ERNs are actively working to implement the Patient Journey approach across all rare conditions, empowering patients to inform care pathways based on their own lived experiences.

A Patient Journey functions both as a method and as a dynamic document. As a method, they involve charting the needs and experiences of patients and caregivers from the clinical presentation and throughout key stages of their healthcare journey, encompassing both medical and psychological aspects. As a document, they offer a visual and detailed matrix of these needs, enhancing communication and understanding between patients and family members and caregivers as well as with the healthcare professionals.

This Guide serves as a “companion” for using the new ERN Patient Journey Templates. As such, it details the key steps and methodology required to support develop high-quality documents ready for approval for recognition as ERN Patient Journeys.

Guide Structure

This Guide is structured into **6 Steps** to aid you develop your Patient Journey. These steps include:





STEP 1: Select Topic & Define Scope

SELECT THE TOPIC

Each European Reference Network covers a cluster of rare conditions. The patient representatives and clinical leads should first discuss and agree which rare conditions should be prioritised to develop Patient Journeys.

Typically, priority is given to conditions where two key conditions are met:

- Willingness and capacity of the patient representatives and clinicians to work on the project.
- Existence, or ongoing development, of a clinical guideline, clinical decision support tool and/or patient pathway.

DEFINING THE SCOPE & TARGET POPULATION

Rare conditions are complex, multi-systemic conditions that require an integrated care approach to address these holistic needs. Therefore, when defining the scope of the Patient Journey a reflection should not be limited to the medical needs but must take a wider perspective to capture the holistic needs for the selected condition for both the individual and the family as a whole.

Rare conditions affect different populations, based upon the specific nature of each condition. First symptoms may appear in early childhood or later in life; a specific conditions may affect either men and women or both, or may affect sub-populations, according to the gene or variant affected or due to co-morbidities, for example. Therefore, it is critical to define the target population or sub-population for each Patient Journey.

Patient Journeys can be developed in a stepwise approach for each sub-population.



Tip: When developing the scope of the Patient Journey, be mindful of capturing the health, psychological and social needs for the selected population.

DEFINE THE STAGES OF THE PATIENT JOURNEY

Patient Journeys do not share standard stages throughout a person's life. Each rare condition has a unique progression and course, from onset through the lifespan of the condition. Therefore, it is important to develop a tailored set of stages of the Patient Journey for each rare condition.

The stages of a condition can include:

- Pre-natal or newborn screening
- Onset of symptoms
- Diagnosis
- First intervention
- Surveillance
- Treatment and/or Surgery
- Transition from childhood to adolescence/adulthood/older adult
- Etc.

DISSEMINATION STRATEGY

Decide the purpose of the Patient Journey and plan a dissemination strategy.

It is recommended to agree on a dissemination and communication strategy through discussion between the patient representatives and the Network. This strategy could include the development of factsheets, infographics and supporting material that makes the Patient Journey accessible to the different audiences, e.g.: parents and family groups or care givers, clinical teams in hospitals etc. This may require the allocation of a budget that can support a graphic designer to design and develop supporting material.



Tip: If you plan to disseminate and use the Patient Journey externally, make sure at this stage to identify all potential uses and secure a budget to cover expenses to design different formats, translation and proofreading.





STEP 2: Characterise each Stage of the Patient Journey

Each stage of the Patient Journey that has been defined in Step 1 needs to be further characterised by describing 4 core elements: **timing of the steps and stages of the journey, clinical presentation, needs and ideal support & best practice.**

Before engaging with your wider community in this effort, it is useful to develop an individual journey. This can be done by one individual or several individuals from different countries, seeking in parallel limited feedback from family members and their closer network if they wish to do so.

Firstly, for each of the stages of the patient journey indicate the timeframe, clinical presentation and associated needs of the person and that of the caregivers or parents, depending on the previously agreed scope. Then, determine what 'good care' and 'ideal support' would look like to address the needs identified at this stage.

NB: Information to define the stages of the patient journey (such as "clinical presentation/symptoms", "patient needs", "ideal support and best practice") differ per stage and should be defined at the beginning of the process for every stage included to develop a Patient Journey.

This table template can be used to characterise each stage of the journey.

STAGE OF JOURNEY	TIMEFRAME	CLINICAL PRESENTATION	NEEDS	IDEAL SUPPORT & BEST PRACTICE



Tip: To further characterise each stage of the journey, it is recommended to capture areas of best practice that might be identified at this stage.

Tip: Engage with a clinical lead in your ERN to review the description of the clinical presentation.

When completed, this first version can then be used to engage with other patient representatives and organisations, to review the contents and develop it into a Patient Journey that accurately describes the common needs for the selected rare condition. Please see Step 3: Engagement with Community.

Additional Resources

[Mapping Patient Journey Template](#)



STEP 3: Engage with your Community

Each Patient Journey is developed to represent the common needs of a specific patient population for a specific condition. They are not individual testimonies but a reflection of the real-world experience of a wider community of individuals living with the same condition. For ERNs, it is recommended that Patient Journeys be developed by engaging with more than 20 people from a minimum of 6 different EU Member States.

SELECT YOUR ENGAGEMENT APPROACH

Different approaches can be used to engage the wider patient community to collect their views, from surveys to semi-structured interviews, online workshops or focus groups. The selection of your engagement approach will depend on the resources available, as well as the scope and the purpose of your Patient Journey.

If resources are limited, it is recommended that persons (at least 20) from 6 different EU countries be asked to individually characterise their Patient Journey. These would then be reviewed by the patient representatives and clinical leads in the ERN who are facilitating the development of the Patient Journey.



Tip: Detail the number of people, their patient organisations as well as their countries of residence in the methodology section of the Patient Journey. This is important for presenting a transparent approach and for demonstrating the independence and quality of the approach taken.

CONSIDER HOW TO PROTECT THE DATA AND PRIVACY OF INDIVIDUALS

All personal data collected in the context of the Patient Journey must be collected and processed on the basis of consent. Individuals taking part in the characterisation of needs (Step 2) or in providing their views in Step 3 must provide their consent for their data to be used.

You should inform participating individuals that all data collected will be pseudonymised and used only for the following purposes: analysis, scientific and statistical research in connection with the development of a Patient Journey to inform the provision of health and social services. The aggregated results thereof may be shared with third parties through conferences, publications, websites, interviews.

Any person providing his/her consent, is at any time free to withdraw their consent for the processing of the personal data, without giving any reason, by notifying the lead in the Network responsible for the development of the Patient Journey. Upon the withdrawal of consent, the processing of an individual's personal data will stop. All data should be stored in a secured database that is accessible only to the members of the Network and the patient representatives responsible for the development of the Patient Journey, and will be accessed only on a strict need-to-know basis.

Additional Resources

[Information on Collecting Data: example from ENDO ERN](#)

[Consent Form: example from ENDO ERN](#)

[Consent Form Template](#)

ANALYSE THE RESULTS TO DEVELOP AN OUTLINE PATIENT JOURNEY

The insights gained from the community need to be analysed and then used to update the individual characterisation developed in Step 2 to develop an Outline Patient Journey that will reflect the collective needs of a community. This Outline can be used as the basis of a consensus building process.

DECIDE WHETHER YOU WANT TO ORGANISE A CONSENSUS EXERCISE

Building consensus using a Delphi approach (which is a systematic process of forecasting using the collective opinion of panel members). A Delphi approach is useful to identify whether there is agreement on the needs or whether there is a difference of views.

The consensus exercise would consist of several rounds or sessions of consensus building with a representation of the wider patient community. After each round of consensus building, the results as well as the reasons provided for agreement/disagreement, are captured in an anonymised summary that is made available as a basis for the next round.



Tip: An online consensus meeting will enable the community to discuss the results and explore any areas of disagreement.

Additional Resources

[EURORDIS' Speak Up, Listen Up & Follow Up Guide on surveys](#)

[EURORDIS Open Academy eLearning course on how to design good surveys](#)



STEP 4: Draft the final Patient Journey

The drafting of the final Patient Journey will be conducted in partnership between the patient representative(s) and the clinical lead (s) in the Network.

The results and insights from the community engagement will be summarised and the final ERN Patient Journey may be drafted using the 'ERN Core Reference Documents' templates. There are two templates available:

1. Detailed Patient Journey (Word document)
2. Visual Presentation Summary of the Patient Journey (Power Point document).

STRUCTURE OF THE DETAILED PATIENT JOURNEY (WORD DOCUMENT)

SECTION	AUTHOR
Overview of the rare condition incl. prevalence and aetiology	Clinical Lead
Methodology	Patient Representative
Overview of the Stages of the Journey	Patient Representative
#1 Stage: Pre-natal or newborn screening*	<ul style="list-style-type: none"> • Clinical presentation section is drafted by the Patient Representative & validated by the Clinical Lead • Needs & Ideal Support sections are drafted by the Patient Representative • Best Practice can be drafted by both the Patient Representative & Clinical Lead
#2 Stage: Onset of symptoms*	
#3 Stage: Diagnosis*	
#4 Stage: etc.*	
Acknowledgements	Patient Representative
References	Both

*Each Patient Journey will contain the stages of the journey specific to the rare condition.

SUMMARY OF THE PATIENT JOURNEY (POWER POINT DOCUMENT)

The detailed Patient Journey will be summarised in a visual presentation of the Patient Journey (Power Point document) to aid engagement and presentation of the journey.

Additional Resources

[ERN Patient Journey Template \(word\)](#)

[ERN Patient Journey Template \(powerpoint\)](#)



STEP 5: Clinical Review & Approval

The final Patient Journey should be reviewed by a clinician who is recognised as an expert for the rare condition in the Network, before being approved for adoption by the ERN.

SECTIONS FOR CLINICAL REVIEW

Clinical validation is important for the following sections of the Patient Journey:

1. Overview of the rare condition including aetiology and prevalence.
2. Clinical Presentations at each Stage of the Journey.
3. Any references and evidence-based information that is included.

SECTIONS EXEMPTED FROM CLINICAL REVIEW

As the Patient Journeys are a reflection and representation of a rare condition through the lived experience of patients, the following sections should not be reviewed by the clinical lead, as these represent solely the insights gained from an affected population or sub-population:

1. Population needs mapped under each stage.
2. What good care and ideal support looks like.

FORMAL APPROVAL BY THE ERN

Following clinical review and validation, the Patient Journey should be approved by the relevant Network governing body, e.g.: Executive or Management Board.

PRODUCTION OF FINAL PATIENT JOURNEY AND ACCOMPANYING COMMUNICATION MATERIALS

The final Patient Journey should be formally presented using the ERN 'Core Reference Documents' for ERN Patient Journeys. Once the Patient Journey has been published, the ERN Coordination team, in collaboration with the clinical and patient leads, can execute the dissemination and communication strategy as planned in Step 1. This could include the development of factsheets, abstracts, infographics and supporting materials that makes the Patient Journey accessible to the different audiences, e.g.: parents, family groups and carers, clinical teams in hospitals, policy makers etc.



STEP 6: Put Your Patient Journey into Action

Patient Journeys are living documents that capture the needs of a specific population. They can be used mainly in two distinct ways:

OUTSIDE THE NETWORK

Continue to use the Patient Journey as a **dynamic document to support continuous two-way engagement** between the patient representatives involved in the ERNs and the wider rare disease community outside the Networks. Patient representatives active in an ERN act as a bridge between the Network and the wider patient community. Their legitimacy is largely grounded in their capacity to understand and represent the common needs and insights of a wider population for a specific or cluster of rare conditions.

The Patient Journey can be used as a tool to raise awareness and support families and non-experts to understand patients' needs over the course of the journey and to communicate what the community considers to be ideal care at each stage. Also, they are a mean to improve the healthcare service, building a strategy and an infrastructure (Patient pathways) according to the unmet needs of a condition-specific population.

INSIDE THE NETWORK

Patient Journeys are a useful tool to **support patient representatives in an ERN** to represent the needs of their community and to mitigate advocating from an individual and personal perspective, thereby increasing their legitimacy and contribution in the Network and help support discussions to be patient centred.

Patient Journeys also offer a tool to enable patient partnerships in the **design of clinical guidelines and patient pathways**, to ensure that they capture the needs for a specific population and identify any gaps in the delivery of care.

Patient Journeys also provide an overview of the population needs for the cluster of rare conditions included in the scope of a given Network that can be used to **inform the prioritisation of resources and plan target activities** to address these needs in the workplan of the Network.

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