



# Patient Journeys Guide & Templates



ePAG advocates and  
ERN project managers

Resource for Implementing Patient Partnership in the European Reference Networks (ERNs)

## 01 Purpose

This guide provides a step-by-step workflow, along with practical tips and templates, to support patient representatives active in the ERNs in developing a Patient Journey for their respective rare conditions.

## 02 How to use it

The guide offers tools and approaches to capture the common needs of people living with a rare or complex condition, from first symptoms to follow-up, and presents them visually in a 'Patient Journey.'

This six-step process enables patient representatives to collaborate with their communities and the clinical leads in the ERNs to create a Patient Journey for their condition.



## 03 Why use it



Patient journeys can be used as a tool to guide the Networks' actions in addressing these needs. They can also assist the community in interactions with clinicians who are not experts in their condition.

Scan the QR code  
or [click here](#)



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