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# PATIENT PARTNERSHIP FRAMEWORK FOR THE EUROPEAN REFERENCE NETWORKS



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## About this Guide

The [European Reference Networks](#) (ERNs) are patient-centred, clinically-led networks that have given health professionals and patient organisations an unparalleled opportunity to co-create better healthcare services and research for persons living with a rare disease.

In 2015 the European Union Committee of Experts on Rare Diseases formally recognised the critical and integral role that patient representatives should play as formal members of the decision-making structures of ERNs [1]. People living with a rare disease draw on their experience from living with a rare or complex condition, and some of them also on knowledge acquired through different trainings, complementing in this way the scientific knowledge from health professionals and building together a critical mass of knowledge and expertise to address some of the most pressing needs of this patient population.

Since the launch of the Networks in 2017, EURORDIS and the rare disease patient community have taken the lead to ensure that the voice of the community is integrated into the governance and strategic and operational delivery of the ERNs through the creation of 24 European Patient Advocacy Groups (ePAGs), which bring together over 300 patient advocates who are actively involved in the ERNs. ePAG advocates play a fundamental role in connecting the Networks with the wider rare disease patient community and, where relevant, championing the diversity of views of the wider patient community relevant to each ERN - not just of their own disease area.

While the European Commission was responsible for establishing the rules for the participation of healthcare providers in the 24 Networks according to the legislation[2], the organisation of patient representation was left to each individual Network. A few ERNs formally included patient representation in their governance structure from the outset, whereas the rest started collaborating with the European Patient Advocacy Groups once the Network was established and progressively integrated the ePAG into the Network's governance structure. Overall, patient partnership in the ERNs has progressively evolved, from a strong emphasis on structuring patient representation in each Network and clarifying the role of ePAG advocates in the early years, to more recently a greater focus on operations and collaboration in different domains.



**Patient partnership in the ERNs** can be defined as a mutual relationship between patients and health professionals, where input from people living with a rare disease or caring for someone with a rare disease routinely and formally informs the Networks' collaborative activities and decision-making. Patient partnership implies considering health professionals and patients involved in the Networks as equal partners in all ERN activities and domains (e.g. Network planning and evaluation, healthcare, training, education, outreach and information, and clinical research).

For the purposes of this framework, we use the term **'patient'** to encompass individuals living with a rare disease and their family members who participate in the ERNs, whether as patient representatives or individually. This terminology is employed to enhance this Guide's clarity and should not be misconstrued as describing individuals who are passively the subject of a rare or complex condition. In this Guide, the term 'health professionals' encompasses clinicians and all other healthcare experts engaged in the ERNs, including physiotherapists, psychologists, researchers, bioengineers, laboratory professionals, and health ethicists.

The term **'framework'** refers to "the ideas, information and principles that form the structure of an organisation or plan"<sup>1</sup>. This framework for the ERNs has been developed with the ambition to guide people in planning for, conducting and evaluating patient partnership in the ERNs. It may also serve as a practical blueprint for patient organisations and other stakeholders partnering in healthcare settings or other clinical networks. It has been co-created by patients, health professionals and project managers involved in the ERNs and EURORDIS. As such, the framework has been designed based on the experience, insights, and perspectives of the main actors involved in this partnership. These views were collated through a [survey](#) (184 respondents involved in the 24 ERNs, of whom 95 were health professionals, 72 were patient representatives and/or individual patients, and 17 were project managers), an online workshop (32 participants, of whom three were health professionals and the rest patient representatives), and written feedback from patients and health professionals involved in the ERNs.

The structure of the framework draws on the patient engagement framework developed by [Health Quality Ontario](#)<sup>[3]</sup>. After stating the overall objective of patient partnership in the Networks, this Guide emphasises the values and beliefs that form the foundation of patient partnership in the ERNs. It then explains the different engagement approaches through which patients and health professionals may collaborate and describes the domains where this collaboration takes place. Finally, it highlights the tools, processes, competencies, and organisational arrangements needed to plan, conduct, and evaluate patient partnership in the ERNs as enablers for a continuous and effective patient partnership.

Together, all these elements form the Patient Partnership Framework for the ERNs and provide a common and mutual understanding of the objective and principles underpinning this Framework. Designed as a practical guide, this will support the Networks to build and maintain a strong culture of patient partnership in their operational activities and strategic decision-making, while duly recognising the contribution of people living with a rare disease in the delivery of the Networks' objectives.



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1. Definition of "framework" from the [Cambridge Academic Content Dictionary](#) © Cambridge University Press

# Have a glance at the Patient Partnership Framework for the ERNs

ERNs must be well-equipped for **collective impact**. Everyone involved should be committed to achieving a common set of goals, using structured collaboration through a centralised support infrastructure with dedicated staff, and processes that enable progress towards a common agenda, continuous communication, shared measurement, and mutually reinforcing activities among all participants [4].

The **overarching goal** of patient partnership in the ERNs is to collaboratively improve healthcare and the lives of people living with a rare or complex condition, taking into consideration their needs and responding to them.

Patient partnership in the ERNs is rooted in a set of principles that provide a foundation for effective collaboration: **mutual respect, learning, complementarity, continuous involvement, shared leadership, teamwork, recognition, and clarity of roles and responsibilities**.

ERNs are clinical networks with a strong focus on clinical care and training, and gradually also on clinical research. Hence, the areas where the collaboration between patients and health professionals takes place are closely related to these domains. Specifically, the domains of collaboration include: network strategy and management, healthcare, training, clinical research and registries, outreach, and communication.

Patients and health professionals involved in the ERNs use a spectrum of **engagement approaches or techniques** to collaborate. These approaches and techniques range from sharing information with patients, consulting patients, involving patients and co-creating. Often a combination of approaches is used at different stages of the same project.

Finally, sustainable patient partnership requires an **enabling environment**, which encompasses tools, competencies, processes, and the right organisational culture to sustain a systematic and continuous collaboration.

## Out of the 184 survey respondents

**99%** joined the ERNs to improve healthcare for people living with a rare or complex condition and 98% continue to be involved in the Networks for this reason

**97%** joined the Networks to increase the knowledge about rare and complex conditions

**96%** continue to be involved in the ERNs to advance research about rare and complex conditions

[EURORDIS Survey on Patient Partnership Framework for the ERNs](#), April 2023.

## THE PATIENT PARTNERSHIP FRAMEWORK FOR THE ERNs

### GUIDING PRINCIPLES

TRANSPARENCY

LEARNING

TEAMWORK

PROFESSIONALISM

COMPLEMENTARITY

MUTUAL RESPECT

CLARITY OF ROLES

SHARED LEADERSHIP

CONTINUOUS INVOLVEMENT



### ENABLERS



#### CULTURE & GOVERNANCE

A governance structure and collaboration culture that facilitates equal patient and clinician involvement in ERN decisions



#### PROCESSES & ORGANISATIONAL ARRANGEMENTS

Processes and organisational arrangements to favour systematic and routine collaboration in the ERNs



#### COMPETENCIES

Knowledge and skills to partner and collaborate effectively to advance towards the ERNs goals



**TOOLS AND RESOURCES** To support and orientate patients and clinicians on how to collaborate and work together

# Discover the 9 Guiding Principles for a healthy partnership

A strong patient partnership culture is built upon trust alongside other key principles that guide the behaviour of the parties when they engage. Patients and health professionals involved in the Networks have identified the following principles to ensure that the collaboration is meaningful to all of them.

## **MUTUAL RESPECT**

Patients and health professionals respect each other, communicate openly, and actively listen to each other. Everyone can openly express their needs, perspectives, and concerns without fear of reprisal.

## **LEARNING**

Patients and health professionals are open to learn about how things may improve and are open to learn from each other.

## **TRANSPARENCY**

Patients and health professionals are transparent about knowledge gaps and about the challenges and constraints that they might face in partnering effectively in the Network.

## **COMPLEMENTARITY**

There is a mutual recognition of the complementarity of scientific, professional, and experiential knowledge that health professionals and patients bring to the table. Both act in ways that demonstrate the value of the input provided by the other party.

## **SHARED LEADERSHIP**

Everyone is aware of the Network's goals and feels empowered to make proposals and take the lead on projects based on their expertise. Patients and health professionals jointly shape and lead the work of the Network and have a shared responsibility for the Network's performance.

## **TEAMWORK**

Patients and health professionals work together from the beginning to set priorities, agree on activities, identify gaps and needs, and cooperate to develop solutions and projects.

## **PROFESSIONALISM**

Patients and health professionals live up to the commitment they have made to contribute to the Network, communicate regularly, and report on the progress of ERN-related projects.

## **CONTINUOUS INVOLVEMENT**

Patients and health professionals work together from the beginning in all ERN collaborative activities and projects.

## **CLARITY OF ROLES AND RESPONSIBILITIES**

The Network has clearly defined the roles, core tasks and responsibilities of patients and health professionals and everyone is kept updated. Health professionals are aware of the different roles of individual patients and of patient representatives that represent a wider community when collaborating with them.

# Identify the areas of collaboration

Depending on the characteristics of the rare diseases and complex conditions that fall under their scope and taking into consideration the eight objectives foreseen in the Cross-Border Healthcare Directive[5] for the ERNs, each Network has defined its own priorities. Regardless of the specific objectives that each individual Network pursues, all 24 Networks seek to improve healthcare for people living with a rare or complex condition and increase the existing knowledge about these conditions. To do so, patients and health professionals involved in the ERNs collaborate across five different domains, namely:



**Network strategy and management**



**Healthcare**



**Training and education**



**Clinical research and registries**



**Outreach and communication**

Identifying the area where the collaboration takes place, and, more precisely, the type of outcome that they are aiming at producing, helps patients and health professionals to decide the best approach to partnering for and organising their collaboration, defining collectively who does what, how and when.

This section highlights examples of good patient partnership in the five different domains.



## NETWORK STRATEGY AND MANAGEMENT

Partnering in the Network's strategy and management implies that patients and health professionals discuss and agree on the priorities of the Network, including resource allocation. Collaboration in this domain also extends to overseeing the implementation of the work plans and monitoring the performance of the Network.



Read this [factsheet](#) to discover how ERN ERNICA patients and health professionals are partnering in the Network's strategy and management.

Other Networks, such as ERN PaedCAN and ERN EURO-NMD, feature similar arrangements that enable patient representatives and health professionals to effectively collaborate in the ERN strategic planning and management. Watch these two videos to find out how this has been organised ([PaedCAN ERN](#); [EURO-NMD ERN](#)).





Partnering in healthcare in the context of the ERNs means that health professionals and patients collaborate in the development of care pathways, clinical practice guidelines, evidence reports, clinical consensus statements, and other tools to support healthcare delivery and disease management.

Some of the knowledge assets developed or curated by the ERNs, such as clinical practice guidelines and consensus statements, may eventually inform the redesign of hospital services, or, more generally, the organisation of care for a given rare or complex disease at national level. Possibly the best strategy to develop these types of products is to orchestrate a mix of engagement mechanisms, including activities to consult the patient community coupled with full collaboration of health professionals and patient representatives involved in the ERNs to co-design these knowledge assets.

The tumour surveillance guidelines for individuals with neurofibromatosis type 1 (NF1), developed by a group of experts in NF1<sup>2</sup> and patient representatives from [ERN GENTURIS](#), may serve to illustrate in practical terms how to partner in guideline development [6]. Listen to an ePAG advocate in this short video as he explains the process. The Consensus Statement on the Management of Patients with Esophageal Atresia and Tracheoesophageal Fistula developed by [ERN ERNICA](#) is another excellent example of how health professionals and patients can co-design such tools to support clinical decision making [7]. Building on the multidisciplinary expertise of four ERNs, child and adult neurologists from [MetabERN](#), [ERN-RND](#), [ERN EpiCARE](#) and [ERN EURO-NMD](#), together with experts from the UK and patient advocates, have drafted a consensus paper on the management of seizures in mitochondrial patients.

Based on these experiences, and on the expertise of the [European Lung Foundation](#) in developing methodologies for the involvement of patients and the public in guideline development [8], EURORDIS has developed a short step-by-step practical guide for ERNs and other organisations to plan the co-development of clinical practice guidelines and consensus statements [9].

Health professionals and patients involved in [ERN ReCONNET](#) have also partnered to develop a methodology to co-design an organisational model for patients' care pathways [10].

Patient journeys are possibly one of the most popular tools used in the ERNs to engage in discussions around standards of care and patients' needs [11]. These journeys illustrate the typical steps facing someone with a rare or complex condition throughout their life. Each journey maps the needs and expectations of patients and their families to the clinical presentations at different stages of the care pathway. As such, they provide an excellent basis to co-create care pathways or plan other ERN activities. For example, since 2022 in ERN ERNICA, the patient journey has been considered the umbrella concept under which all the ERN collaborative activities sit.



[Read this factsheet](#) to discover how patient representatives and health professionals involved in ERN EpiCARE have used patient journeys as a basis to develop standards of care for all patients with a rare or complex epilepsy.

Patient representatives and health professionals in many ERNs have engaged in this activity and have published the journeys: [ERN EpiCARE](#), [ERN CRANIO](#), [Endo-ERN](#), [ERKNet](#), [ERN GENTURIS](#), [ERN ITHACA](#), [ERN Lung](#), [ERN RITA](#), [ERN-RND](#).

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2. Neurofibromatosis type 1 (NF1) affects mainly skin and nerves. Individuals with NF1 have darker coloured spots (birthmarks) on the skin. They develop non-cancerous tumours along the nerves of the skin, and other regions of the body. Individuals with NF1 have an increased risk for several other rare tumours. Females with NF1 between 30 and 50 years have a higher chance of developing breast cancer. NF1 affected people also have an increased risk of high blood pressure and skeletal problems such as a high curvature of the spine. Many children have some form of learning disability, concentration or communication problem (check [ERN GENTURIS website](#) for more information).

## EDUCATION AND TRAINING

This area is possibly the one where the greatest number of activities have been organised since the launch of the Networks. Today, all ERNs have a regular education and training programme for clinicians. Throughout the year, they organise webinars and courses, and they have also organised a short-term exchange programme.

The collaboration in this area has primarily materialised in the development of joint [webinars](#) targeted at health professionals and/or patients, where clinicians and patients involved in the ERN present and discuss on the same topic, bringing their complementary knowledge and experience to the audience. [ERN ReCONNET](#) is a good example of how patients and clinicians routinely partner to deliver educational webinars. [ERN EURO-NMD](#) has produced a series of [educational videos](#) on rare peripheral neuropathies to raise awareness, primarily among general practitioners. These videos contain patient testimonials as well as explanations from clinical experts in the field of rare peripheral neuropathies.

Patients and clinicians in different Networks have also collaborated in the design and delivery of educational activities that seek, among other things, to train health professionals on aspects related to the burden of living with a given disease. For example, ERN Skin clinicians and patient representatives designed a [training session on Cutis Laxa](#) that included a session where patients shared with participants the daily burden of living with this disease.

## CLINICAL RESEARCH AND REGISTRIES

Partnering in clinical research and registries means that health professionals and patients involved in the ERNs collaborate in the development of clinical research and patient registries.

The collaboration in clinical research activities has not yet fully taken off in the ERNs, but there are already good examples of collaboration in this area, specifically around the revision of Orphanet's classification of rare diseases and the development of ERNs' registries.



Read this [factsheet](#) to discover how ERN eUROGEN health professionals, at the initiative of the ePAG representatives, worked with Orphanet to review and update the nomenclature and classifications for anorectal malformations. Many other ERNs have also worked, or are working with, Orphanet to update the nomenclature and classification of different groups of disorders. A complete list by ERN can be found in this [report](#) of the [OD4RD](#) project (pages 9-10). Read this [factsheet](#) to discover how the ERN EURO-NMD Patient Advisory Board (PAB) has contributed to the ERN registry since its inception in 2019.



## INFORMATION AND OUTREACH

This is possibly the domain where health professionals and patients involved in the ERNs have collaborated the most. Patient partnership in this domain ranges from collaborating in the creation of informational resources for patients and families to outreach and awareness raising initiatives targeted at the rare disease community and beyond.

Patients and health professionals in many ERNs have worked together to produce information resources, mainly in English, for health professionals, people living with a rare disease and families, and have made them available on their websites.

Patient representatives and health professionals involved in the [VASCERN Pediatric and Primary Lymphedema Working Group](#) have developed together a flowchart on Cellulitis for patients with lymphedema. The combined experience and the deep connections of the patient representatives with their communities helped to develop a resource that was both comprehensive as well as practical and easy to use.

In ERN EpiCARE, patient representatives and health professionals have also collaborated in the development of informational [leaflets on rare epilepsies](#) for patients, families and health professionals. These leaflets provide precise and accessible information on rare and complex epilepsies and how to manage care, with one part targeted at health professionals, and another part for patients and their families.

Likewise, ERN GUARD-Heart health professionals have developed [layperson summaries](#) of some of the Network's publications that were reviewed by patient representatives; virtually all their suggestions were taken into consideration and incorporated in the final versions.



Read this [factsheet](#) to discover how ERN PaedCAN has strengthened and formalised the partnership with the patient representatives involved in the Network through a contract to enhance the integration of patients in the activities of the Network, including supporting the referrals to the multidisciplinary tumour virtual board.

[ERN ERNICA](#) and [ERN eUROGEN](#) have translated a [website](#), originally co-created by Dutch experts and people living with a rare disease, that has been adapted for an international audience and offers sexual advice and support for people living with anorectal malformation or Hirschsprung's disease.



# Explore engagement approaches

Creating and managing patient partnership in the ERNs for collective impact requires using different methods, depending on the specific activity at hand. Health professionals and patients can choose from a spectrum of engagement approaches depending on the purpose and the specific outcome that is sought.

Typically, engagement approaches or techniques are presented as a progressive continuum of 'actions' that range from sharing information with patients to co-creating in full collaboration, while the consultation and involvement of patients to deliberate certain matters both fall in the middle of the spectrum [3], [12], [13].



The fact that some methods imply a lower form of engagement does not mean that they are less valuable if they are the best match to serve a specific purpose. The patient partnership survey results indicate that in the ERNs there is some consensus around this principle. 68% of the survey respondents indicated that sharing information with patients, consulting patients and collaborating routinely on an equal basis were all valid engagement approaches, depending on the activity at hand.

The key to a successful partnership is to match the right technique to the right situation[13], by routinely discussing what is needed, and who needs to do what, when and how.

## SPECTRUM OF ENGAGEMENT APPROACHES



### SHARE

Where health professionals share easy-to-understand information with people living with a rare disease, their families and their representatives, to help manage a given condition, and inform about new treatments, surgical procedures, or any other health-related matter.



### CONSULT

Where health professionals engage with people living with a rare disease, their families and their representatives to consult them on the health professionals' perspective on different ERN-related projects, such as their needs throughout the care pathway.



### INVOLVE

Where people living with a rare disease or patient representatives actively participate or collaborate with health professionals to plan, implement, monitor and evaluate ERN-related projects and activities. "The last word" lies with the health professionals.



### CO-CREATE

Where people living with a rare disease, their families and their representatives and health professionals partner to plan, implement, monitor and evaluate activities. Decisions are jointly taken.

It is not always straightforward to find the best approach and understand when and how to use the different engagement approaches. Not surprisingly, 93% of the respondents to the survey recognise the importance of having access to resources on how to engage and work better.

*"Patient organisations and healthcare professionals involved in the ERN are very open to work in the best possible way, even if we don't always know how." (ePAG lead)*

*"When you know what patient partnership is and how you can put it into practice, then it comes as a habit." (ERN project manager)*

To enable a fruitful partnership in any given activity, it is critical to set out at the beginning of any activity or project where and how patients and health professionals will be involved. ERN project managers have an instrumental role to play in this regard, beyond managing a given activity. Ideally, they should ensure that patients and health professionals agree on how a given activity or project will be organised and that everyone understands when and how each of them will contribute. To ensure this, ERN project managers should be familiar with different engagement approaches, existing resources and good practices on patient partnership, and techniques to enhance and facilitate meaningful patient partnership in all ERNs' collaborative activities.

Often, the best approach is to use a combination of methods. The involvement of patients in the different stages leading to the development of clinical practice guidelines may serve to illustrate how a combination of engagement approaches looks in practice (see figure 3) [9].



ERN CRANIO has set up a patient-clinician engagement group where patients and clinicians, covering various specialties and collaborating in different projects, come together to identify ways in which the Network's priorities can be achieved in partnership.



## TECHNIQUES TO PARTNER WITH PATIENTS IN CLINICAL PRACTICE GUIDELINE DEVELOPMENT, BASED ON EURORDIS PRACTICAL GUIDE

### 1. PREPARATION



#### CO-CREATE

- Include 1-2 patient representatives in the Guideline Committee as core members.
- Create a Patient Guideline Advisory Group (PAG) with 8-10 patient representatives, ideally from different countries. They will secure broader engagement with the wider patient community. The 2 patient representatives that sit on the Guideline Committee will Chair this group.



#### CONSULT

- On priorities and important aspects to people living with a rare disease to define the guideline topic (survey to wider patient community or other consultation means).
- On aspects important to people living with a rare disease to help develop the PICO question, highlighting questions or aspects which are important from their perspective (survey to wider patient community or other consultation means).
- On outcomes that matter to people living with a rare disease (rating/voting).

### 2. RESEARCH



#### CONSULT

- If additional perspectives from people living with a rare disease should be sought and how these will be integrated (engage with the Patient Advisory Group to agree on this aspect).



#### SHARE

- The emerging findings of the systematic review and identify gaps in the evidence that could be covered through different approaches such as interviews, focus groups or patient-centred literature search.

### 3. DRAFT



#### INVOLVE

- Patient representatives in the formulation of the recommendations based on the evidence, in order to capture their views and preferences when weighing up the benefits and harms of a recommended intervention. Use the results from patient literature reviews, survey data or the views of the wider PAG to consider wider perspectives.



#### SHARE

- Draft guideline for review to check that views from people living with a rare disease have been well incorporated.



#### CO-CREATE

- Integration of input from people living with a rare disease in final manuscript or separate publication.
- Include the 2 patient representatives sitting in the Guideline Committee as co-authors and note others in acknowledgments (lighter involvement).

### 4. IMPLEMENT



#### CO-CREATE

- Dissemination and implementation plan, including the development of measures and actions to measure implementation and allow for continuous improvement.
- Lay-persons version of the clinical practice guideline.



#### CONSULT

- On implementation roadmap (survey wider patient community or other consultation means).



#### SHARE

- Lay-persons version across patient community.

# Discover the enablers of effective patient partnership

Patient partnership does not happen spontaneously. There are perceptual barriers as well as more practical barriers related to organisational arrangements, processes and skills that if left unaddressed, will hamper any meaningful collaboration between patients and health professionals [14], [15]

Research and grey literature [3], [16]–[19] on patient engagement in healthcare settings provide a great deal of insight into enablers or facilitators for patient partnership and offer tips on techniques to enhance design of engagement, create a receptive context and enhance patients' input[20].

For the purpose of this framework, facilitators to support patient partnership are organised in three categories:

1. **Culture and governance**
2. **Processes and organisational arrangements**
3. **Competencies (knowledge and skills)**

A non-exhaustive list of tips, tools and resources, organised by category and purpose, is available in Annex I.

## ENABLERS FOR PATIENT PARTNERSHIP



### CULTURE & GOVERNANCE

A governance structure and collaboration culture that facilitates equal patient and clinician involvement in ERN decisions



### PROCESSES & ORGANISATIONAL ARRANGEMENTS

Processes and organisational arrangements to favour systematic and routine collaboration in the ERNs



### COMPETENCIES

Knowledge and skills to partner and collaborate effectively to advance towards the ERNs goals



### TOOLS AND RESOURCES To support and orientate patients and clinicians on how to collaborate and work together



The top 4 enablers to support patient partnership in the ERNs indicated by the survey respondents were: (i) a strong culture of partnering with patients in the ERN clinical leads and coordination team (95%) (ii) governance structure and processes that allow patients and health professionals to be equally involved in the ERN decision-making and priority setting (95%) (iii) access to resources on how to engage and work together, such as practical guides and good practices (93%) and (iv) training for health professionals, patients and ERN coordination teams on how to involve patients in the ERN activities and decision making (87%).

# Learn how to use this Guide for your ERN

This Guide may serve the ERNs to build their own patient partnership strategy, strengthen their patient partnership culture and ensure that this culture is truly embedded in all the Network's collaborative activities and decision-making structures.

1. Reflect to what extent the different activities planned in the ERN are contributing to the overarching goal of the partnership.
2. Consider how to observe and implement the 9 Guiding Principles for a healthy partnership in all the Network activities.
3. Identify the domain where a given collaborative activity takes place and seek to adopt a consistent partnership approach across all domains and ERN collaborative activities.
4. Outline systematically the different engagement techniques that will be used in all stages of a project, clarifying roles and responsibilities (preparation, implementation, evaluation and feedback). Plan for continuous engagement throughout the different stages of a project.
5. Build an enabling ecosystem, and identify what key enablers are missing or need to be enhanced in your Network.
6. Measure and celebrate the achievements of your partnership!

EURORDIS remains dedicated to sustaining support for patient partnership within the ERNs, actively participating in the identification, curation, and development of necessary resources and tools. These efforts aim to foster regular and systematic collaboration between patients and healthcare professionals within the Networks.



**83%** of the survey respondents continue to be involved in the Networks because they feel excited about what partnership between patients and health professionals in the ERNs can accomplish


**90%** continue to be involved because they want to work with patient and patient representatives






# Annex I Enablers for an effective patient partnership

CATEGORY	PURPOSE	ENABLERS	AVAILABLE TOOLS & RESOURCES
 GOVERNANCE AND CULTURE	<b>Build a culture of continuous improvement supported by a rigorous evaluation of the impact of patient partnership.</b>	<ul style="list-style-type: none"> <li>• Integrate oversight of patient partnership into the overall ERN governance oversight process, including encouraging each person to fully exercise their role and responsibilities within the team. Monitor and measure impact of patient partnership to show results.</li> <li>• Set up a governance structure that truly allows patients and health professionals to be equally involved in the ERN decision-making and priority setting. For example, in some ERNs, all Working Groups (WGs) are led by a tandem of a clinician and a patient lead.</li> <li>• Establish rules to implement alternative and flexible ways for patients and health professionals to engage in the ERNs (see EURORDIS <a href="#">governance templates</a> to structure patient representation in the ERNs).</li> <li>• Establish an onboarding process for new health professionals and patients to guide them on how patient partnership is organised in the Network, providing clear role descriptions and how they are expected to collaborate. Include a good introduction to the ERN system as a whole.</li> <li>• Formalise the role of patients in the ERN governance and provide a clear description of their role and responsibilities. (Communicate clearly about their role!).</li> <li>• Organise a call every two months between the patient group and the ERN Coordinator and ERN project manager to discuss problems and horizon-scanning. Strengthen the feedback loop with patient representatives.</li> <li>• Establish an oversight process to jointly reflect on projects, achievements, identify gaps and bottlenecks, and discuss measures to address them (for example, the ERN PaedCAN Oversight Committee). Celebrate and acknowledge good results and progress.</li> <li>• Organise regular reflection sessions where patients and clinicians come together to assess and work on their collaboration by identifying and solving problems, and plan follow-up actions together to improve their partnership (see EURORDIS <a href="#">guidance</a> on how to organise and manage these kind of sessions).</li> <li>• Develop monitoring and an evaluation framework to measure impact of patient partnership to show results.</li> </ul>	<ul style="list-style-type: none"> <li>• EURORDIS <a href="#">governance templates</a> to structure patient representation in the ERNs.</li> <li>• EURORDIS <a href="#">guidance</a> on how to organise and manage reflection sessions.</li> <li>• Set of basic indicators to capture the participation of patient reps in some of the ERNs activities. <a href="#">Link here</a>. <i>ReCONNET, ITHACA and Rita ePAGs have developed surveys to capture the information needed.</i></li> <li>• <a href="#">PPI monitoring and evaluation framework, University College Dublin</a>.</li> <li>• <a href="#">Evaluation toolkit</a> resource that features 27 evaluation tools for patient engagement in health care and health research and instruments searchable by user type (whether you are a researcher, a patient partner or a healthcare organisation)</li> </ul>
 PROCESSES	<b>Ensure continuous involvement</b>	<ul style="list-style-type: none"> <li>• Establish a standard planning process to enable early and continuous engagement, that allows jointly deciding who will contribute to what and when, and to sustain the collaboration throughout the projects.</li> <li>• Develop a checklist for the standard planning process that can be used across ERN activities or adapted to make patient partnership business as usual. This could follow a four-point planning process: (i) Preparation -purpose, resources, timeframe, participants, etc.; (ii) Design - techniques/engagement approaches, role of participants, etc.; (iii) Implementation; and (iv) Evaluation and feedback.</li> <li>• Establish a process to collect illustrative examples on patient partnership to share within the ERN and across ERNs.</li> </ul>	<ul style="list-style-type: none"> <li>• <a href="#">Practical Guide</a> for partnership in guideline development available.</li> <li>• <a href="#">Short guide</a> for partnership activities in basic pre-clinical translational &amp; social research projects.</li> <li>• Resources and tools to support patient partnership in translational research are available at the <a href="#">Patient Engagement Resource Centre (PERC)</a>.</li> </ul>

CATEGORY	PURPOSE	ENABLERS	AVAILABLE TOOLS & RESOURCES
	Identify patient representatives to ensure succession and cover gaps	<ul style="list-style-type: none"> <li>Establish a clear and transparent process to recruit new patient representatives.</li> <li>Organise ad hoc recruitment campaigns to cover gaps where needed.</li> <li>Establish an oversight process to ensure that all steps to recruit new patient representatives and patients are duly followed.</li> </ul>	<ul style="list-style-type: none"> <li>EURORDIS <a href="#">governance templates</a> to structure patient representation in the ERNs.</li> </ul>
	Share widely and re-use information produced by the ERN	<ul style="list-style-type: none"> <li>Dedicate adequate resources for translation allocated in the ERN budgets: IT tools complemented by native speaker review.</li> <li>Develop a knowledge management and outreach strategy: Organise the information on the website, categorise your content and share information using different channels and formats - social media, emailing, websites, webinars etc.</li> </ul>	
	Capture the patient community needs	<ul style="list-style-type: none"> <li>Establish a process for the needs assessment of people living with a rare disease as opposed to the ongoing report of needs.</li> <li>Support patient representatives to capture and analyse the voice of their communities.</li> <li>Establish a process to monitor how the input from patients has been integrated in the ERN deliverables.</li> </ul>	<ul style="list-style-type: none"> <li>Practical Guide to capture and analyse the community needs and perspective available <a href="#">here</a>.</li> <li>EURORDIS open-ended questionnaire to collect the information for the patient journeys and legal guidance to collect the data in Belgium, The Netherlands, Spain, Portugal Germany and France. All resources and templates to develop patient journeys available <a href="#">here</a>/page 19</li> </ul>
 <b>ORGANISATIONAL ARRANGEMENTS</b>	Facilitate planning and time management for health professionals and patients	<ul style="list-style-type: none"> <li>Require all ERN WGs to establish an annual roadmap of activities and tentative calendar for the year to allow patients and health professionals to organise, get prepared and distribute their workload. This roadmap should be developed jointly. This is also a way to agree on what needs to be done and the priorities.</li> </ul>	
	Plan for inclusiveness	<ul style="list-style-type: none"> <li>Systematically plan for hybrid meetings whenever an ERN WG meeting is organised as a side event of a face-to-face meeting, to allow all patient representatives to connect and contribute.</li> <li>Be sensible to accessibility needs and plan accordingly (special organisational arrangements).</li> </ul>	
	Develop a balanced number of activities for all diseases under the scope of the Network	<ul style="list-style-type: none"> <li>Include in the annual work plan of the ERN a balanced number of activities for all diseases under the operational scope of the ERN. (There are expert centres in the ERN covering the disease).</li> </ul>	

CATEGORY	PURPOSE	ENABLERS	AVAILABLE TOOLS & RESOURCES
	<b>Build relationships</b>	<ul style="list-style-type: none"> <li>• Supplement formal interaction with informal interactions to build relationships. For example, these could include networking opportunities in ERN face-to-face meetings, but also webinars on topics of interest for patients and health professionals.</li> <li>• Set opportunities for interaction at regular frequencies, organise debriefings after meetings, and provide support to track follow-up actions to show progress between meetings.</li> <li>• Map patient representatives' competencies and make health professionals more aware of the patient representatives' skills/competencies. For example, short bios of the patient representatives could be uploaded to the website as well as shared with WGs' leads. The information could be collected as part of the patient representative application process.</li> <li>• Pair more experienced patients with newcomers so that they feel supported.</li> <li>• Organise meetings at the national level where the ERN experts and the patient community can come together to share and connect.</li> <li>• Use the ERN podcast, blog and newsletter to feature interviews conducted by or with clinicians and ePAG leads.</li> </ul>	
	<b>Secure in-house competencies for patient engagement</b>	<ul style="list-style-type: none"> <li>• Hire a dedicated patient engagement manager to join the ERN coordination team to support patient partnership: <ul style="list-style-type: none"> <li>– ERN PaedCan model: The ERN has hired a patient engagement manager from one of the patient organisations involved in the ERN.</li> <li>– ERN EURO-NMD model: The ERN's Patient Advisory Board has hired a patient engagement manager who liaises and works with the ERN coordination team.</li> <li>– Other ERNs have hired a patient representative to perform this role.</li> </ul> </li> </ul>	
 <p><b>COMPETENCIES (KNOWLEDGE AND SKILLS)</b></p>	<b>Acquire relevant knowledge and foster soft skills</b>	<ul style="list-style-type: none"> <li>• Training for all on ERN processes and IT tools to ensure proper implementation and use.</li> <li>• Joint training for patient representatives and health professionals on topics of common interest, e.g. health data, patient-centred outcome measures, cross-border healthcare etc.</li> <li>• Joint training for patient representatives and health professionals on soft skills, such as teamwork, communication and active listening skills, providing feedback, negotiating to facilitate consensus building, conflict prevention etc.</li> <li>• Training for patient representatives – from being a “patient” to being a representative of their community in the ERN. It is very important also to reset the relationship between the patient/family members and the health professionals – from ‘patient-my treating clinician’ to ‘patient representative-clinician’ in an ERN setting, by improving patient representatives' soft skills – for example, providing constructive feedback.</li> </ul>	
	<b>Secure in-house competencies for patient engagement</b>	<ul style="list-style-type: none"> <li>• Peer learning and training for ERN project managers on how to operationalise patient partnership across the different areas of work of the ERNs.</li> </ul>	

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