



This hub hosts resources to help you plan and implement patient partnership in healthcare networks. It includes good practices, guides, tools and resources to build your partnership skills.

You may search resources by keyword, area of work or type of resource.

Start exploring now!

HOW TO FIND RESOURCES IN THE PATIENT PARTNERSHIP HUB

Search by **keyword**

Keywords are terms that can help you find information, tools and resources about a specific topic.

These are some examples of keywords that you could use: Patient Journeys, Evaluation, Patient reported outcome measures, PROMs, Foundations, Patients' needs, Clinical Practice Guidelines, CPGs, Governance, etc.



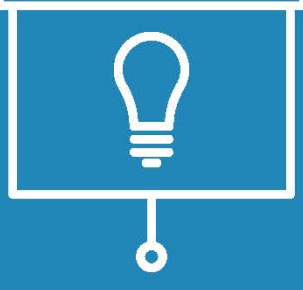
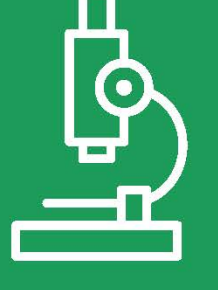

You can use multiple keywords to narrow down your search.

Search by **area of work**

Areas of work refer to the main activity domains of healthcare networks where the collaborative work takes place.

To browse resources by area of activity, first you must **untick** the area or areas that you would like to **discard** from your search.

The active search areas will remain coloured while the discarded ones will appear in grey.

 <p>Network strategy and management</p> <p>Partnering to establish the priorities of the Network, including resource allocation, overseeing the implementation of the work plans and monitoring the performance of the Network.</p>	 <p>Healthcare</p> <p>Partnering to develop tools & resources to improve healthcare (e.g. care pathways and other clinical decision support tools, clinical practice guidelines, standards of care, outcome measures, etc.).</p>	 <p>Education and Training</p> <p>It refers to the skills and knowledge required from staff (e.g. Network project manager), health professionals and patient representatives to build and implement successful patient partnerships in healthcare.</p>	 <p>Clinical research and registries</p> <p>Partnering in planning and developing clinical research activities, creating and managing patient registries.</p>	 <p>Information and outreach</p> <p>Partnering in the creation of informational resources for patients and families and outreach materials aimed at the rare disease community and beyond.</p>
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Search by **type of resource**

We have classified the resources based on their nature, inherent characteristics and intended purpose.

To browse by type of resource, first you must **untick** the type or types of resources that you would like to discard from your search.

The active types in your search will remain coloured while the discarded ones will appear in grey.

 <p>Guidance</p> <p>Resources that provide advice and recommendations on how to plan and implement patient partnership in the Networks activities and projects.</p>	 <p>Good practice</p> <p>Examples or case studies that describe strategies, approaches, or activities that illustrate meaningful patient partnership in the Networks.</p>	 <p>Tool</p> <p>Resources that help to operationalise patient partnership in healthcare networks. Where relevant, they include the reference to the guidance or methodological framework they are based on.</p>	 <p>Skills</p> <p>Resources to learn and acquire abilities to facilitate patient partnership in healthcare networks.</p>
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Thank you!

We sincerely appreciate the dedication of the ERN patient representatives and project managers who have collaborated in the development of this Hub. Your efforts make a difference, and we couldn't have achieved this without you!

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