

Criteria to select Patient Partnership Good Practices

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What is the definition of a good practice?

Good practices refer to a collection of strategies, approaches, or activities that lead to success or meaningful outcomes. These practices are proven to be effective, efficient, sustainable, and transferable, achieving the desired results¹. Very often, they are seen as an innovation in comparison to previous methods or approaches.

What is a good patient partnership practice in the European Reference Networks (ERNs)?

A good patient partnership practice in the context of the ERNs can be defined as a set of strategies, approaches, or activities that are driven by ERN patient representatives and clinicians 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. These practices have proven to be effective at achieving the desired outcome, producing long-lasting impact and have potential for being transferable.

Considering the [Patient Partnership Framework for the ERNs](#), a good practice in patient partnership will need to embody all or most of the **guiding principles** for a healthy partnership (i.e. transparency, learning, teamwork, professionalism, complementarity, mutual respect, clarity of roles, shared leadership, continuous involvement) and make use of the most appropriate **engagement approaches** (i.e. share, consult, involve, co-create) to foster collaboration in the selected area.

The goal of capturing patient partnership good practices in the ERNs

The goal of capturing good patient partnership practices is to frame lessons, based on experience, in a manner that will facilitate re-use in future areas of work and/or in other ERNs. EURORDIS aims to capture and disseminate good practices in patient partnership to showcase the value of partnership, facilitate learning from experience and encourage peer learning and exchange among ERNs.

How does EURORDIS ERN and Healthcare team select good practices?

EURORDIS ERN and Healthcare team is continuously scouting for good practices in the different areas of activity of the ERNs. The team typically looks at the following criteria to select good practices:

1. The activity contributes to **achieving the ERNs patient partnership overarching goal** i.e. “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”;

¹ Definition of “good practice” based on the definition of the [European Commission website on integration](#)

2. The project features a **mix of ERN patient representatives and clinicians**. Where relevant, the activity might also include the wider patient community and/or individual patients and family members;
3. People involved in the activity have observed all or most of the **9 guiding principles** for a healthy partnership and can illustrate how they have done so;
4. The **objectives, purposes, actions and results** can be **clearly described**;
5. People leading the project are able to explain which engagement approaches were used and how they were implemented. For the sake of transferability, being **clear about the collaborative techniques used** throughout a given project is as important as the result;
6. The **impact** of the partnership has been measured or at least the added value of the partnership has been captured – for example, by reflecting on how the result would have differ in the absence of partnership;
7. There is potential for **transferability** to other ERNs;
8. The activity or approach is **innovative** in the sense that it has not yet been widely implemented throughout the ERNs;
9. People leading the activity or approach are able to clearly identify the **lessons learned** and **enabling factors** that have eased the good practice (i.e. context factors that were present such as cultural aspects and governance, processes/administrative arrangements, knowledge and skills);
10. The project has used existing resources and **patient engagement tools and guidance** or **has produced new resources or guidance for patient engagement**.

If you identify any patient partnership good practice in your ERN that meet these criteria, please feel free to share them with your EURORDIS ERN focal point or drop us an email at PEM-ePAGs@eurordis.org