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PATIENT PARTNERSHIP FRAMEWORK FOR THE EUROPEAN REFERENCE NETWORKS

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.

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

GUIDING PRINCIPLES

TRANSPARENCY

LEARNING

TEAMWORK

PROFESSIONALISM

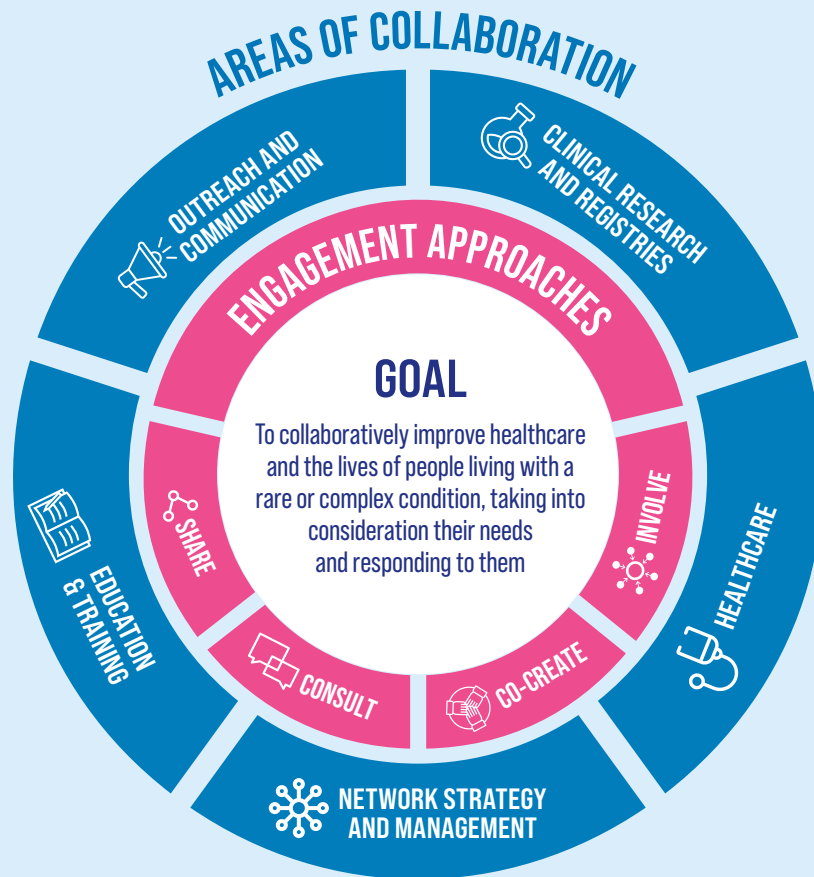
COMPLEMENTARITY

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