

Governance Templates



ERN Coordination team and ePAG leads

Resource for Managing and Supporting Patient Partnership in the European Reference Networks (ERNs)

01 Purpose

Establish clear rules to organise patient involvement in the ERN including the requirements, obligations and responsibilities of the patient organisations and patient representatives involved in the ERNs.

02 How to use it

The ERN Coordination team and the European Patient Advisory Group (ePAG) leads may review the templates and agree on how to adapt them to their needs before submitting a proposal to the Network Board. Good awareness of these rules by everyone involved in the ERN is key for their implementation.

The templates can be used at any point in time when the ERN wishes to review or update its rules on patient representation.

03 Why use it

Having a clear set of rules that are systematically implemented is a building block for good patient partnership. It helps to clarify roles, responsibilities and requirements for patient organisations, individual patients and patient groups to partner with the ERNs.

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