

PATIENT PARTNERSHIP FRAMEWORK FOR CLINICAL TRIALS IN THE EUROPEAN REFERENCE NETWORKS (ERNs)



PURPOSE

The Patient Partnership Framework for Clinical Trials aims to enhance collaboration between people living with a rare or complex condition and health professionals across all stages of clinical trials conducted within the European Reference Networks (ERNs).

The primary objective is to integrate insights of people living with a rare or complex condition all along the research and drug development process, ensuring that clinical trial outcomes are more relevant and patient-centred.

WHY TO USE IT

As clinical trials expand within ERNs, this framework will be a game-changer for embedding patient partnership in clinical trials.

It builds a culture of true partnership, ensuring clinical trials not only meet the needs of people living with a rare or complex condition, but also actively partner with health professionals at every step.

Using this framework will help you to plan how to operationalise this partnership from start to finish.

HOW TO USE IT

This framework is designed as a practical guide for clinical trial teams to successfully partner with people living with a rare or complex conditions using different methodologies at every stage of a clinical trial.

It offers practical step-by-step support during the operational phases of clinical trial for systematic, sustainable, and impactful patient partnership.

The framework offers flexibility for customisation based on the context of each clinical trial. Clinical trial teams will be able to choose at each step the most relevant alternatives from a range of engagement options.

TARGET USERS

The clinical trial team, including the Principal Investigator, and people living with a rare and complex condition involved in the trial can use it as practical guide to plan and organise their partnership throughout the different phases of the clinical trial.

Patient partnership can go from identifying research priorities to influencing trial design, ethical review, and dissemination of results. However, this engagement must be plan ahead to balance the valuable input people can provide with the potential burden that such involvement may place on them.



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