

Summary of the project

European Reference Networks (ERN) are virtual networks bringing together healthcare providers across Europe to tackle complex or rare medical conditions that require highly specialized treatment and a concentration of knowledge and resources. Most of the ERNs are actively working in the domain of development or implementation of Clinical Practice Guidelines (CPGs) with different levels of maturity or organisational approaches. While some of the networks are already in the phase of implementation or adaptation, other ERNs are starting to set-up their plans and priorities. There are as well important differences between networks on the number of existing CPGs or Clinical Decision Support Tools (CDSTs) in the different domains of expertise and in the methodological knowledge and capacity to elaborate, appraise or evaluate such tools.

The overall purpose of this Programme is to provide assistance to the ERNs and their healthcare providers in the process of development, appraisal and implementation of CPGs and CDSTs taking in account the objectives and criteria set under the framework of Article 12 of Directive 2011/24/EU on patients' rights in cross-border healthcare and relevant implementing measures and procedures.

The Programme is structured in 4 Work Packages (WPs) whose general and specific objectives are detailed below:

Work package A. - Advisory Body and Expert panels on CPGs and CDSTs: establishment, maintenance and support. The specific objectives are:

1. To provide technical advice and guidance to the European Commission, to the Member States and to the ERN Coordinators on the overall process of development, appraisal and implementation of CPGs and CDSTs by the creation of an Advisory Body.
2. To support and help the ERNs to carry out the process of development, appraisal and implementation of specific CPGs and CDSTs in each of the 24 approved ERNs by the definition of the model, characteristics and rules of the Expert panels in charge of the CPGs and CDSTs at Network level.

Work package B: Preparation of the methodologies for the development, appraisal and implementation of clinical practice guidelines and Clinical Decision Support Tools. The specific objective is:

1. To prepare the methodologies for the development, appraisal and implementation of CPGs and CDSTs, ensuring that it is based on the state of the art and the recommendations and practices recognised at EU and international level. The methodologies set will comprise a toolkit including guidance documents,

practical tools and recommendations to the Expert panels of each of the 24 approved ERNs and in general to the healthcare professionals' community.

Work package C: Training and capacity building. The specific objectives are:

1. To offer expert training and support to the CPGs contact points and the members of the Expert panels of the 24 ERNs for the appropriate use of the methodologies to be developed under WP B.
2. To offer and provide basic training to all clinical experts, patients and other possible stakeholders involved in the development of CPGs and CDSTs for specific diseases and conditions.
3. To produce training materials in online formats for self-evaluation and training in the field of the development, appraisal and implementation of CPGs and CDSTs available to the entire healthcare community and other interested stakeholders and experts.

Work package D: Support to the development, and appraisal of CPGs and CDSTs. The specific objectives are:

1. To provide support and guidance for the real development and appraisal of CPGs and CDSTs to the 24 contact points on the matter and to the members of the Expert panels of the 24 ERNs.
2. To test and evaluate the utility and effectiveness of the methodological framework and tools for the development and appraisal of CPGs and CDSTs and to include improvements when needed.