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Capacity building of the European Reference Networks to develop and adapt clinical decision-making tools addressing rare diseases: the ERN-Clinical Guidelines Programme.

In a meeting held in Brussels last 6th February, the Commission introduced a new project to provide technical assistance to the ERNs for the development, appraisal and implementation of Clinical Practice Guidelines (CPGs) and Clinical Decision Support Tools (CDSTs). This 4 years contract will enable the ERNs to adopt a common methodology and develop their own decision-making tools: 48 new CPGs are expected and 120 existing CPGs will be adapted to the specific rare diseases they are addressing.

The workshop gathered Coordinators and clinical experts from the 24 ERNs with the European Commission and the consortium led by Fundacion Progreso y Salud winner of the tender and responsible for the implementation of the whole project.

Most of the ERNs are already active and are either producing or adapting existing CPGs or CDSTs. Three ERNs (ERN Reconnet, ERN eUROGEN and ERN TransplantChild) illustrated their experience in this field at the meeting. Altogether, during 18 months - between early 2018 and mid 2019 - the ERNs have adopted more than 650 CPGs and CDSTs, written 11 new CPGs and 54 new CDSTs. However, they present different levels of maturity and organisational approaches: some ERNs are in the phase of implementation or adaptation of decision-making tools, whereas others are starting to set their priorities and plans. Needs are quite diverse, depending on the rare diseases concerned: whereas some decision-making tools sometimes do exist for some diseases and only need to be disseminated, in other cases it is necessary to adapt existing clinical guidelines to the specificities of the diseases. In other cases, there is simply not evidence enough to draft clinical practice guidelines and other decision-making tools like consensus of experts or recommendations are needed..

Starting from the ERNs' needs and the state of the art, the consortium will propose to work on a common methodology and will deliver training activities, to propose a quite harmonized way of proceeding across the ERNs and to support their own capacities to produce decision-making tools. It will also assist them in the production of 2 new CPGs and review of 5 decision-making tools per network with a total of 48 new CPGs and the adaptation of 120 existing CPGs during the duration of the contract. The work will adapt itself to the quite diverse situation depending on the networks and will be flexible.



The participants addressed also several key aspects, like the question of copyrights when existing CPGs are owned by scientific societies, possible conflicts of interest. The Joint Research Center presented the relevant work already developed and now extended in the field of Cancer screening clinical guidelines. Orphanet also pointed out the importance of liaising the work of the ERNs on CPGs and CDMTs with the more than 500 guidelines published on their website, and to coordinate dissemination efforts.

The contract comes from a need identified by the Working Group on Knowledge generation, which gathers representatives of several ERNs and Member States. Given the diversity of approaches of the ERNs in this field, a common way of proceeding was identified as necessary, also to better define the ERNs specificity in this important area of work. The capacity to increase the number of decision-making tools in the field of rare diseases is important to allow health professionals to have good and reliable decision making tools to better diagnose and identify treatments for their patients affected by rare diseases. It is crucial to share the information within the scientific and clinical community to spread the knowledge in a field where expertise is scarce. Finally, CPGs and CDMTs are a necessity to ensure the future and invest in young generation.