



Parallel session PS 7: “Clinical guidelines and knowledge generation”

22 November 14:20 – 15:50

<p>Session leaders:</p> <ul style="list-style-type: none"> ✓ Maurizio Scarpa, ERN MetabERN coordinator ✓ György PFLIEGLER, member of the ERN BoMS, Hungary 	<p>Chair:</p> <ul style="list-style-type: none"> ✓ Maurizio Scarpa, ERN MetabERN coordinator
<p>Speakers:</p> <ul style="list-style-type: none"> ✓ György PFLIEGLER, Member of the ERN BoMS, Hungary ✓ Henrietta FARKAS: Medical doctor and clinician ✓ Mariana DATES, Optimity Consultancy ✓ Ursula Plöckinger (Charité University , Berlin, Germany) ✓ Enrique Terol, Unit B3, DG SANTE 	<p>EC support official:</p> <ul style="list-style-type: none"> ✓ Enrique Terol, Unit B3, DG SANTE

Aim of the parallel session:

The session will allow for a discussion and exchange of views on the strategy, the means and the audiences to be targeted linked to the ERNs’ environment and the community of healthcare providers, patients and other stakeholders dealing with rare and low prevalence and complex diseases.

- Discuss the current state of art of the development and methodologies of the Clinical Practices Guidelines and other possible Clinical Decision Support Tools (CDST) in the case of rare and low prevalence and complex diseases and to discuss the value of and the way forward to develop an ERNs’ CPG and other CDST system.
- To present a mapping of the current state of art of the taxonomy and concepts used in the field of CPG and CDST at international level.
- To have an overview of the activities and deliverables of the ERNs developed in this domain.
- To have an exchange of views on the importance and needs of developing a training and education strategy for the ERNs.

Main issues to be addressed:

- Towards a common ERNs methodology to develop CPG and CDST: Clinical practice guidelines (CPG) are systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances. There is evidence on a) the impact of the use of clinical practice guidelines in terms of better healthcare outcomes and less variability of clinical medical practice, b) the impact on better efficiency on the use of the healthcare resources.
- How to address the challenge of the scarcity of evidence in the area of rare diseases. The development of CPG for rare diseases represents a challenge due the lack of sound evidence and low number of publications and systematic reviews of evidence.
- Training and education, towards an ERNs strategy: Knowledge generation and dissemination is a fundamental field of work for the ENRs. The training and education highlights linked to the ERNs goals and activities are going to be addressed by the speakers as well.

Format / Dynamic of the session:

Short presentations followed by discussion between the panellists and session of Q&A with the audience. The session will cover two main topics.

State of play

- State of play of the actions developed by the EU to support the implementation of the CPG and other CDST (the taxonomy project and the ongoing call for the CPG contract (E. Terol)
- The first outcomes of the work developed on taxonomy and the mapping exercise on the state of play of CPG at international level and how the ERNs are addressing the issue (M Dates)
- The methodological approach and the development and implementation of clinical guidelines at national level by a highly specialised institution: (U. Plöckinger)

The view of the players

- The perspective of the clinicians: challenges and opportunities for the implementation of CPG at the clinical level (H Farkas)
- The perspective of the Member States on the value of the CPG and knowledge generated by the ERNs, how should be organised/ addressed at national level (G Pfliegler)
- The perspective of the ERNs Coordinators: Knowledge Generation (CPG - and other CDST- and eTraining and eLearning) as the backbone of the ERNs (M Scarpa)

Debate, questions from the chair and open discussion with the audience