II European Reference Networks Conference

From planning to implementation

Lisbon 8-9 October 2015
Agenda (28.09.15)

8th October

08:30-09:30	Registration and welcome coffee

09:30-09:35	**Welcome address** *Xavier Prats Monné; Director General of DG SANTE*

09:40-11:05 — **Roundtable I**

Framework for the establishment of European Reference Networks (ERNs)
Introduction by the Chair: *Andrzej Rys; Director Health Systems and Products; DG SANTE*

09:50-10:10	*Implementation process: timeline and milestones*	*Enrique Terol; DG SANTE*
10:10-10:30	*Manual for Technical Assessment of the ERNs*	*Louise Clement and Matt Johnson; PACE-ERN Consortium*
10:30-10:50	*Approval of Networks: the ERNs Board of Member States*	*Till Voigtländer; Co-chair Board of Member States [Clinical Institute of Neurology, Medical University Vienna]*
10:50-11:05	*Debate & Questions*	

11:10-12:15 — **Roundtable II**

European Reference Networks: strategic value for the Member States
Chair: *Anne Calteux; Ministry of Health Luxembourg*

11:15-11:30	*Strategic value of ERN for France*	*Patrice Dosquet; Ministry of Health France*
11:30-11:45	*Strategic value of ERN for Portugal*	*Alexandre Diniz; Ministry of Health Portugal*
11:45-12:00	*Strategic value of ERN for Lithuania*	*Arimantas Tamašauskas; Lithuanian University of Health Sciences*
12:00-12:15	*Debate & Questions*	

Ministerial high level roundtable
ERN an strategic value for the EU citizens and health care systems

12:15-13:00	**Xavier Prats Monné;** Director General of DG SANTE **Paulo Macedo;** Minister of Health of Portugal **Lydia Mutsch;** Minister of Health of Luxembourg

13:00-14:00	**Lunch break and Poster Session**

14:00-15:00	**Roundtable III**

Network organisational challenges and experiences: issues, solutions and lessons learned
Chair: *Peter O'Donnell; Healthcare Journalist at POLITICO*

14:05-14:20	Rare Diseases Networks: lesson learned, grouping diseases	*Kate Bushby; EUCERD Joint Action*
14:20-14:35	The network coordinator view	*Ruth Ladenstein; Expo-R-Net pilot network*
14:35-14:50	The patients views	*Yann le Cam; EURORDIS patient organisation*
14:50-15:00	Debate & Questions	

15:00-15:30	**Coffee break and Poster Session**

15:30–16:30	**Roundtable IV**

ERN and better health outcomes: Good clinical practices
Chair: *Jorge Penedo; Ministry of Health Portugal*

15:35-15:50	Healthcare guidelines, recommendations, clinical pathways	*Paola Laricchiuta; Istituto Superiore di Sanità, National Centre for Rare Diseases*
15:50-16:05	Evidence-based practices and rare / low prevalence diseases	*Domenica Taruscio; Istituto Superiore di Sanità, National Centre for Rare Diseases*
16:05-16:20	Continuous Clinical Improvement and performance and outcome indicators	*Karen Ritchie; Healthcare Improvement Scotland*
16:20-16:30	Debate & Questions	

16:30–17:20	**Roundtable V**

Network Challenges: eHealth and IT solutions
Chair: *Jaroslaw Waligora; DG SANTE*

16:30-16:55	*WEB technology for collecting, handling and elaborating data: The SIOPEL experience*	*Piotr Czauderna; SIOPEL and Expo-R-Net member*
16:55-17:15	*Sharing information on Healthcare across Europe - Lessons from EXPAND*	*Henrique Martins; EXPAND project coordinator*
17:15-17:20	*Debate & Questions*	

	Closing remarks	
17:20-17:30	*Conclusions and call for action*	*Enrique Terol; DG SANTE*

9th October

Plenary session

How to perform a self-assessment and prepare for a strong application?
Chair: *Enrique Terol; DG SANTE*

09:00-10:00   *Overview and presentation of the assessment process*   *Louise Clement, Paula Greco;*
                     and tools   *PACE-ERN Consortium*

                     Debate & Questions

Parallel Workshops *Technical support and facilitation provided by the European Observatory on Health Systems and Policies*

10:00-13:00   ***Workshop 1 - How to prepare a successful proposal to build an ERN?***
                     This session should help to get a good understanding of what is needed to pull together a
                     good proposal and what specific challenges that could be encountered in the process.

10:00-13:00   ***Workshop 2 - How to develop, use and appraise clinical decision making tools?***
                     This session should help to get a good understanding of what would be expected of both
                     the networks and their members in terms of developing good practice guidelines and
                     patient pathways and similar tools.

10:00-13:00   ***Workshop 3 – Clinical Research in a Network Environment***
                     This session should help to get a good understanding of what is the added value of ERNs
                     for clinical research and what would be the challenges of performing research in a
                     network environment.

10:00–13:00   ***Workshop 4 - Rare Diseases Networks: lessons learned, grouping diseases and patient***
                     involvement
                     This session should help to get a good understanding of how based on the extensive
                     experience of working in networks in rare diseases field broad thematic ERNs can be
                     developed and how patients can be effectively involved in them.

8th & 9th October

Poster exhibition of Network Experiences

A selection of best practices and previous experiences of pilot Networks will accessible in the
foyer of the Conference

10:00-13:00: Workshop 1 - How to prepare a successful proposal to build an ERN

Facilitator:	*Willy Palm; Health Observatory of Health Systems*
Experts:	*Barbara Brunmair; ExPO-r-Net pilot Network (rare cancers in children)*
	Philipe Ryvlin; E-Pilepsy pilot Network
	Luca Sangiorgi; Coordinator of a network on Rare Skeletal Diseases
	Reinhard Holl, network on rare diabetes in children
	JLL Vives Corron, ENERCA network on rare anaemias
	Louise Clement, Paula Greco; PACE-ERN Consortium

This workshop will explore some of the main governance issues and challenges related to developing an ERN application. For this it will draw on the lessons learned from existing pilot networks. More specifically this session will look into

- the governance model to be developed for running an ERN
- the practical steps that need to be taken to prepare a proposal

10:00-13:00: Workshop 2 - How to develop, use and appraise clinical decision making tools

Facilitator:	*Suszy Lessof;* European Observatory on Health Systems and Policies**;**
Experts:	*Michele Hilton-Boon; University of Glasgow*
	Paola Laricchiuta; Istituto Superiore di Sanità, National Centre for Rare Diseases
	Karen Ritchie; Healthcare Improvement Scotland
	Domenica Taruscio; Istituto Superiore di Sanità, National Centre for Rare Diseases
	Charles Bruneau, Matt Johnson; PACE-ERN Consortium

This workshop will particularly focus on the requirement as specified in the Delegated Decision for ERNs to offer a high level of expertise and have the capacity to produce good practice guidelines and to implement outcome measures and quality control. More specifically the session will

- explore how various tools and best practices to support health professionals, patients and carers in choosing the best available therapeutic options within the specific context of rare, low prevalence and complex diseases, can be developed, implemented and appraised within the context of ERNs.
- define the kind of services and activities that ERNs could develop under this heading and explore the challenges they may encounter.

10:00-13:00: Workshop 3 – Clinical Research In a Network Environment

Facilitator:	*Irene Glinos; European Observatory on Health Systems and Policies*
Experts:	*Silvia Deandrea; Joint Research Center, European Commission*
	Pascale Flamant; UNICANCER
	Mauricio Scarpa; Expert in clinical trials in rare diseases
	Samantha Parker; Lysogene
	Denis Lacombe; EORTC

This workshop will particularly focus on the requirement as specified in the Delegated Act for ERNs to contribute to research. More specifically the session will

- explore the various tools and ways to organise clinical research in a network environment.
- reflect on how collaboration in clinical research with various stakeholders, especially the industry, could be organised and framed.

10:00-13:00: Workshop 4 - Rare Diseases Networks: lessons learned, grouping diseases and patient involvement

Facilitator:	*Matthias Wismar; European Observatory on Health Systems and Policies*
Experts:	*Kate Bushby; EUCERD Joint Action, Newcastle University*
	Victoria Hedley; EUCERD Joint Action, Newcastle University
	Yann Le Cam; EURORDIS
	Teresinha Evangelista; EUCERD Joint Action, Newcastle University
	Stephen Lynn; EUCERD Joint Action, Newcastle University

This session will focus on the specific needs and challenges of the rare diseases fields to engage in the establishing of ERNs. More specifically the session will

- discuss the added value and specific challenges of developing thematic networks for groups of rare diseases.
- specify the involvement of patients and the development of a patient-centred approach in ERNs for rare diseases.