II European Reference Networks Conference

from planning to implementation

Lisbon 8-9 October 2015
Draft agenda (26.08.15)

8th October

08.30-09.30	Registration and welcome coffee

09.30-09-35	**Welcome address** Andrzej Rys Director Health Systems and Products; DG SANTE
09.35-09:45	**Opening speech** *Xavier Prats Monné; Director General of DG SANTE*
09:45-11:10	**Roundtable I**

Framework for the establishment of European Reference Networks (ERNs)
Chair: *Andrzej Rys; 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]*
10.50-11.10	*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	**Paulo Macedo** Minister of Health of Portugal **Lydia Mutsch** Minister of Health of Luxembourg **Xavier Prats Monné;** Director General of DG SANTE

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

8th October

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	_Yan 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	Health care 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_

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*
and tools

Debate & Questions

Parallel Workshops

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

10:00-13:00   *Workshop 2 - Rare Diseases Networks: lessons learned, grouping diseases and patient involvement*

10:00-13:00   *Workshop 3 - How to develop, use and appraise clinical decision making tools ?*

10:00–13:00   *Workshop 4 - Research In a Network Environment decision making tools ?*

9th & 8th 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