

II European Reference Networks Conference

from planning to implementation

Lisbon 8-9 October 2015

Draft agenda (17.07.15)

8th October

08.30-09.30

Registration and welcome coffee

09.30-09-35

Welcome address

09.35-09:45

Opening speech

Andrzej Rys; Director Health Systems and Products; DG SANTE

09:45-11:10

Roundtable I

Framework for the establishment of European Reference Networks (ERNs)

Chair: Maria Iglesia; Health Systems Head of Unit; 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 Matt Johnson and Charles Bruneau; 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 Ministry of Health Portugal (tba)

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

12.15-12:45

ERN an strategic value for the EU citizens and health care systems

12:45-14:00

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	<u>Kate Bushby; EUCERD Joint Action</u>
14:20-14:35	The network coordinator view	<u>Ruth Ladenstein; Expo-R-Net pilot network</u>
14:35-14:50	The patients views	<u>Yan le Cam; EURORDIS patient organisation</u>
14:50-15:00	Debate & Questions	

15:00-15:30

Coffee break and Poster Session

15:30 – 16:30

Roundtable III

ERN and better health outcomes: Good clinical practices

Chair: Jorge Penedo; Ministry of Health Portugal

15:35-15:50	A taxonomy of Clinical Decision Making Tools: guidelines, protocols, recommendation	<u>Paola Laricchiuta, Istituto Superiore di Sanità, National Centre for Rare Diseases</u>
15:50-16:05	Evidence based practices and rare / low prevalence diseases	<u>Domenica Taruscio, Istituto Superiore di Sanità, National Centre for Rare Diseases</u>
16:05-16:20	Continuous Clinical Improvement and performance and outcome indicators	<u>Karen Ritchie, Healthcare Improvement Scotland</u>
16:20-16:30	Debate & Questions	

16:30 – 17:20

Roundtable V

Network Challenges: eHealth and IT solutions

Chair: Jarek Waliqora; DG SANTE

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

Closing remarks

17:20-17:30	<i>Conclusions and call for action</i>	<u>Director General for Health & Food Safety (tba)</u>
-------------	----------------------------------------	------------------------------------------------------------

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 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*