



European
Reference
Networks

European
Observatory 
on Health Systems and Policies
a partnership hosted by WHO

How to develop, use and appraise clinical decision making tools

Parallel Workshop 2

2nd ERN conference, Lisbon, 9 October 2015

European
Observatory 
on Health Systems and Policies



1 Workshops and facilitators

1. How to prepare a successful ERN proposal -
- 2. How to develop, use and appraise clinical decision making tools**
3. How to develop clinical research in a network environment
4. How to build thematic and patient-centred rare disease networks



2 Clinical decision making tools team

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



3(a) Workshop objectives (generic)

- Identify and discuss key challenges for developing an ERN proposal
- Define network's scope, objectives and activities in specific fields or areas
- Explore how to translate operational network criteria and evidence needed



3(b) Workshop objectives (specific)

- Identify and discuss how clinical decision making tools fit in an ERN proposal
- Define how a network can take on or add value to the development of clinical guidelines and the implementation of supports to decision making
- Explore how to meet the expectations of the application process (the operational network criteria) and respect the evidence



4(a) Workshop approach

- Overview of challenges
- Short presentations / case studies
- Practical discussion of ERN application
- Feed-back on lessons and suggestions
- Experts to share their experience
- Participants to actively engage with issues
- Rapporteur to summarise outcomes
- Facilitators to help focus on ERN applications



4 (b) Workshop programme

- **Introduction**
- **Guidelines and decision making tools as part of ERN**
 - Matt Johnson
- **Clinical guidelines, patient pathways and the ERN perspective**
 - Domenica Taruscio and Paola Laricchiuta
 - Group discussion / Feed-back
 - Key lessons for your own network plans
 - 2-3 messages for the Commission in developing the process
- **Implementing clinical decision making tools**
 - Karen Ritchie and Michele Hilton-Boon
 - Group discussion / Feed-back
 - Key lessons for your own network plans
 - 2-3 messages for the Commission in developing the process
- **Conclusion**



5 (a) Clinical guidelines and the ERN

Think of how you would organise a process for appraising existing clinical guidelines and developing clinical guidelines that the network member could all use. Examples of the types of issues to consider include

- What core tools and (cross-border) activities are needed?
- What challenges and potential benefits stem from working in thematic networks (of groups of rare diseases)?
- How can activities be linked to and communicated with national activities and actors (national networks, medical associations)?
- How would a network measure its performance in this field?
- How do patients' groups fit in?



5(b) Implementing clinical decision making tools

Think about how to develop a implementation plan for clinical decision making tools within the network

- Which clinical decision making tools (recommendations, protocols, pathways, referral procedures) suit the Network best?
- What responsibilities might network members have for implementing established guidelines and pathways? How might networks monitor implementation?
- How can multidisciplinary and patient-centred approaches to implementation be shown?
- How would you establish clear diagnostic and referral pathways for patients within the network (and between networks)?
- How do virtual tools (telemedicine, virtual medical boards) allow knowledge rather than patients to travel?



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