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Workshop 2: How to develop, use and appraise clinical decision making tools

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Note: This document has been developed in the frame of a service contract signed between EURORDIS as contractor and Consumers, Health, Agriculture and Food Executive Agency (Chafea) as contracting authority. The opinions expressed in this document are those of the contractor only and do not represent European Commission's or Chafea 's official position.

Clinical guidelines and the ERN perspective

Group discussion 1

Operational Criteria

Organisation of the Operational Criteria

Proposed European Reference Networks

General Criteria and Conditions to be fulfilled:

1. Governance and Coordination
2. Patient Care
3. Multidisciplinary Approach
4. Good Practice, Outcome Measures, and Quality Control
5. Contribution to Research
6. Continuous Education, Training, and Development
7. Networking and Collaboration

Development and monitoring of
clinical guidelines at the Network
level

Member Applicants

General Criteria and Conditions to be fulfilled:

1. Patient Empowerment and Patient-Centred Care
2. Organisation, Management, and Business Continuity
3. Research, Education and Training
4. Expertise, Information Systems, and e-Health Tools
5. Quality and Safety

Specific Criteria and Conditions to be fulfilled:

1. Competence, Experience and Outcomes of Care
2. Human Resources
3. Organisation of Patient Care
4. Facilities and Equipment

GOOD PRACTICE, OUTCOME MEASURES, AND QUALITY CONTROL

Legislated Requirement

2014/286/EU Annex I (4) (c)

Criteria

4.2 The Network develops and implements clinical guidelines and cross border patient pathways.

Operational criteria measures.

- a) The Network has a formal process for developing and/or disseminating clinical guideline.
- b) When developing and/or selecting clinical guidelines, the Network obtains patient and family input.
- c) The Network develops patient pathways, including cross border pathways, in collaboration with its Members.
- d) The Network monitors implementation (of established clinical guidelines and patient pathways to encourage consistent use across its Members and monitor their appropriateness. Information is used to make on-going quality improvements.)

Operational Criteria (sample)

Measure:

- a) The Network has a formal process for developing and/or disseminating clinical guidelines.

Guideline

Clinical Guidelines comprise recommendations on the care of patients with specific conditions, based on the best available research, evidence, and practice/experience. Where there are nationally, regionally, or locally agreed upon requirements or existing clinical guidelines in place, the Network adopts these requirements, where appropriate.

The **process for developing and/or selecting** clinical guidelines should be based on **sound and robust methodological criteria** and avoid misunderstandings on the evidence based value of clinical guidelines and other possible clinical making decision tools like **consensus or recommendations of experts**.

That may include using content experts; a consensus panel; Grades of Recommendation Assessment, Development and Evaluation (GRADE); or the Appraisal of Guidelines Research and Evaluation (AGREE) II instrument, which allows Networks to **evaluate** the methodological development of clinical guidelines from six perspectives: scope and purpose, stakeholder involvement, rigor of development, clarity and presentation, applicability, and editorial independence.

Evidence: Clinical Guidelines

Operational Criteria (sample)

c) The Network develops patient pathways, including cross border pathways, in collaboration with its Members.

Guideline

The Network obtains input from its Members, national experts and involved stakeholders like patient associations and scientific societies to identify areas of focus.

The pathways should include relevant contact points for services, hospitals, and multidisciplinary teams at referral, diagnosis, care and treatment, transition, and follow-up.

Evidence

Patient Pathways in Place

Cross Border Pathways

GOOD PRACTICE, OUTCOME MEASURES, AND QUALITY CONTROL

Legislated Requirement

2014/286/EU Annex I (4) (a)-(b)

Criteria

4.1 The Network offers specialised clinical expertise and produces good practice guidelines (for rare or low prevalence complex diseases or conditions).

Operational criteria measures:

- a) The Network gathers, exchanges, and disseminates (knowledge, best practice evidence, and clinical expertise) within and outside of Network.
- b) The Network shares expertise and supports healthcare providers (in order to bring (local, regional and national provision of) care to patients closer to home.
- c) Representatives from each Member meet annually to review and share (best practices, and discuss new evidence-based treatments, therapies, and health care technologies).

Operational Criteria (sample)

Criteria

4.1 The Network offers specialised clinical expertise and produces good practice guidelines for rare or low prevalence complex diseases or conditions.

Measure

The Network gathers, exchanges, and disseminates knowledge, best practice evidence, and clinical expertise within and outside of Network.

Guideline

A variety of tools may be used by Networks to disseminate knowledge, best practice evidence, and clinical expertise. These include: discussion groups or forums for case discussion between experts and a non-expert healthcare professional; web/teleconferencing; intranet sites used a repository for draft documents under discussion by experts; and professional FAQs, etc.

Evidence

Tools used and best practices shared within/outside the Network

Questions?

- What would be a **core set of tools and activities** needed for this?
- What are the **challenges and potential benefits** of doing this within the context of thematic networks (of groups of rare, low prevalence and complex diseases)?
- How should these activities be **linked and communicated with national activities and actors** (e.g. national networks, medical associations)?
- How would a **network measure its performance** in this field?

Questions?

- Which are the **clinical decision making tools** (recommendations, protocols, pathways, referral procedures etc.) that are most suited for actual application within the Network?
- How would you **define responsibilities of network members** to implement established guidelines and pathways and how would you monitor implementation?
- How would you demonstrate the **multidisciplinary and patient-centred** approach in implementing clinical decision making tools?
- How would you **establish clear diagnostic and referral pathways** for patients within the network (and even between networks)?
- As the knowledge rather than patients should travel how do you envisage the **use of virtual tools (telemedicine, virtual medical boards) for the management of cases?**

Thank you.