

2nd CONFERENCE ON

 **European
Reference
Networks**

From planning to
implementation

**8-9 OCTOBER
2015, LISBON**

GOVERNO DE PORTUGAL | MINISTÉRIO DA SAÚDE | GRAND DUCHY OF Luxembourg
Presidency of the Council of the European Union

European Reference Networks

**Implementation process:
timeline and milestones**

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The road to ERNs



Imagine if the best specialists from across Europe could join their efforts to tackle complex or rare medical conditions that require highly specialised healthcare and a concentration of knowledge and resources.



**THE
POWER
OF AN
IDEA**

The road to ERNs



2002
Free
movement of
patients

2005
High Level Group
on Health
Services and
Medical Care
Centres of
Reference report

2006
RD Task Force
Working Group
on centres of
reference

Public Health
Programme
First pilot
networks
projects

2011
Directive
application of
patients' rights
in cross-border
healthcare
Article 12 ERN

2013
Eucerd
Recommendations
European
Reference
Networks (Rd
Erns)

2014
Commission
Decisions on
ERN



European
Reference
Networks



Chapter IV Cooperation between MS Article 12 European Reference Networks

Networks of healthcare providers aiming at
Improving quality and safety and access to highly specialised healthcare

✓ Patients affected by rare or low prevalence and complex diseases

✓ multidisciplinary approach (different specialities/areas of knowledge)

✓ Added value at EU level

✓ Need of cooperation:

- Scarcity knowledge
- Need education
- Complexity / high cost
- Effectiveness in the use of resources

European Reference Networks (ERN): aim of Article 12:
(Directive Patient's Rights to Cross border Healthcare)

Support the development of ERN

Commission

Member States

SHARED  RESPONSIBILITY



17.5.2014

EN

Official Journal of the European Union

L 147/71

What

COMMISSION DELEGATED DECISION

of 10 March 2014

setting out **criteria and conditions** that European Reference Networks and healthcare providers wishing to join a European Reference Network must fulfil

(Text with EEA relevance)

(2014/286/EU)

17.5.2014

EN

Official Journal of the European Union

L 147/79

COMMISSION IMPLEMENTING DECISION

of 10 March 2014

setting out **criteria** for establishing and evaluating European Reference Networks and their Members and for facilitating the exchange of information and expertise on establishing and evaluating such Networks

(Text with EEA relevance)

(2014/287/EU)

How

Entry into force 27 May 2014

Key features of the Networks

- ✓ *Patient centered and clinically lead*
- ✓ *10 Members in at least 8 Countries*
- ✓ *Strong independent (3rd party) assessment*
- ✓ *Fulfillment of Network and Members criteria*
- ✓ *Endorsement and approval by National Authorities (grouping and strategic value)*





Healthcare providers:

Principal constituents of the ERN

- ✓ *Cooperation amongst themselves in a field of expertise*
- ✓ *Accordance with legislation of their Member States*
- ✓ *Fulfillment of the criteria*
- ✓ *Responsibilities and tasks defined in the **governance bodies of the ERN***
- ✓ ***Hub (interconnector)** between national healthcare providers and the ERN*

6 sets of Criteria for Networks



5 sets of general criteria for members



2 sets of specific criteria for members



Networks criteria and capacities



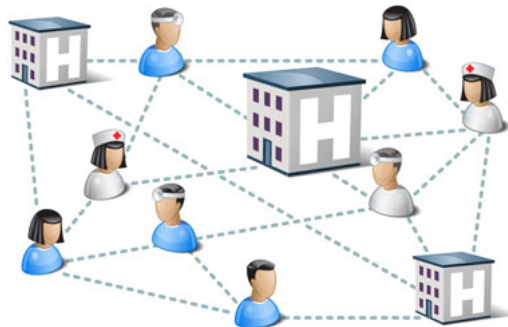
- ✓ *knowledge and **expertise to diagnose, follow up and manage patients***
- ✓ *Evidence of **good outcomes***
- ✓ ***multi-disciplinary** approach*
- ✓ *capacity to **produce good practice guidelines and to implement outcome measures and quality control***
- ✓ ***Research, teaching and training***
- ✓ *collaborate with **other centers of expertise and networks***

Governance / coordination Networks



- ✓ *Transparent and effective coordination & governance*
- ✓ *Flexibility and key organizational features.*

European Reference
Network



Board of the Network

Network Coordinator

Centre
Representative

Centre
Representative

Collaborative
National Centre

Associated National
Centre

Scientific
Societies

Patients
Organisations

Academy

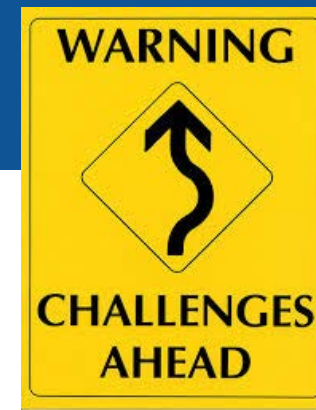
Other
stakeholders

How are things going?



- ✓ *More than **50 interested groups** or pilot networks identified*
- ✓ ***Dynamic interaction** of stakeholders with MS and Commission*
- ✓ ***Preparatory work** of Network proposals ongoing*
- ✓ ***Interaction among professionals** of the same thematic diseases groups*
- ✓ *Active implication of **EU patients and professional/scientific societies***
- ✓ ***Strong support** of the Commission advisory groups (in particular the RD expert group)*
- ✓ *Close **cooperation between Board of MS and Commission***

Challenges



- *Attract and approve the right ERNs*
- *Effective Network model & useful platforms and tools*
- *Commitment of Member States and sustainability*
- *Avoid fragmentation and overlapping*
- *Develop & use standardised tools (clinical guidelines, registries, patient pathways, interoperable IT systems)*

*To involve healthcare professionals, health authorities, managers and patients in a **common project** of ERNs.*



Value and content

What: *epidemiology, thematic group of diseases, type of services*

Why: *demonstration of added value and technical reasons*

Who: *type of players (heterogeneity, consortiums, subareas of specialisation, etc)*

How: *Criteria to be fulfilled **a)** as Network **b)** as member*

Assessment of Networks proposals will focus on how well the proposal is envisaged and defined (as Networks are “in general” not set up so far)

Network proposals: Preparatory and strategic activities

- ✓ ***Strengthening the network value and capacities:***
 - ❑ Multidisciplinary
 - ❑ Avoid fragmentation: Grouping of diseases
 - ❑ Identify mature and clear EU added value type of diseases
 - ❑ Discuss and *Identify other players, partners and members*

- ✓ ***Liaison with MS authorities*** (contact with ERN board representative at national level and discuss !!)

Network proposals: Preparatory and strategic activities

- ✓ Agree on the **specific criteria** for each area of expertise
- ✓ **Define the services of the Network**
- ✓ ***Self-assessment exercise*** (*Network and members*)
- ✓ Define ***Pathways*** *models, referral criteria, clinical decision tools*
- ✓ ***Plan an Information system***



How to assess and approve the Networks?



Players

Healthcare providers

Member States

Commission

Assessment process and Assessment Bodies



Assessment elements



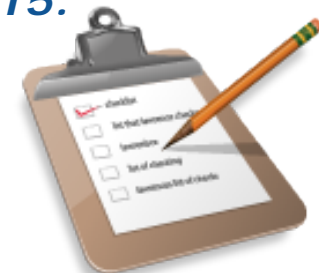
Assessment Manual and tool box

- Application forms*
- Operational criteria*
- Guidance & tools for applicants and assessment bodies*

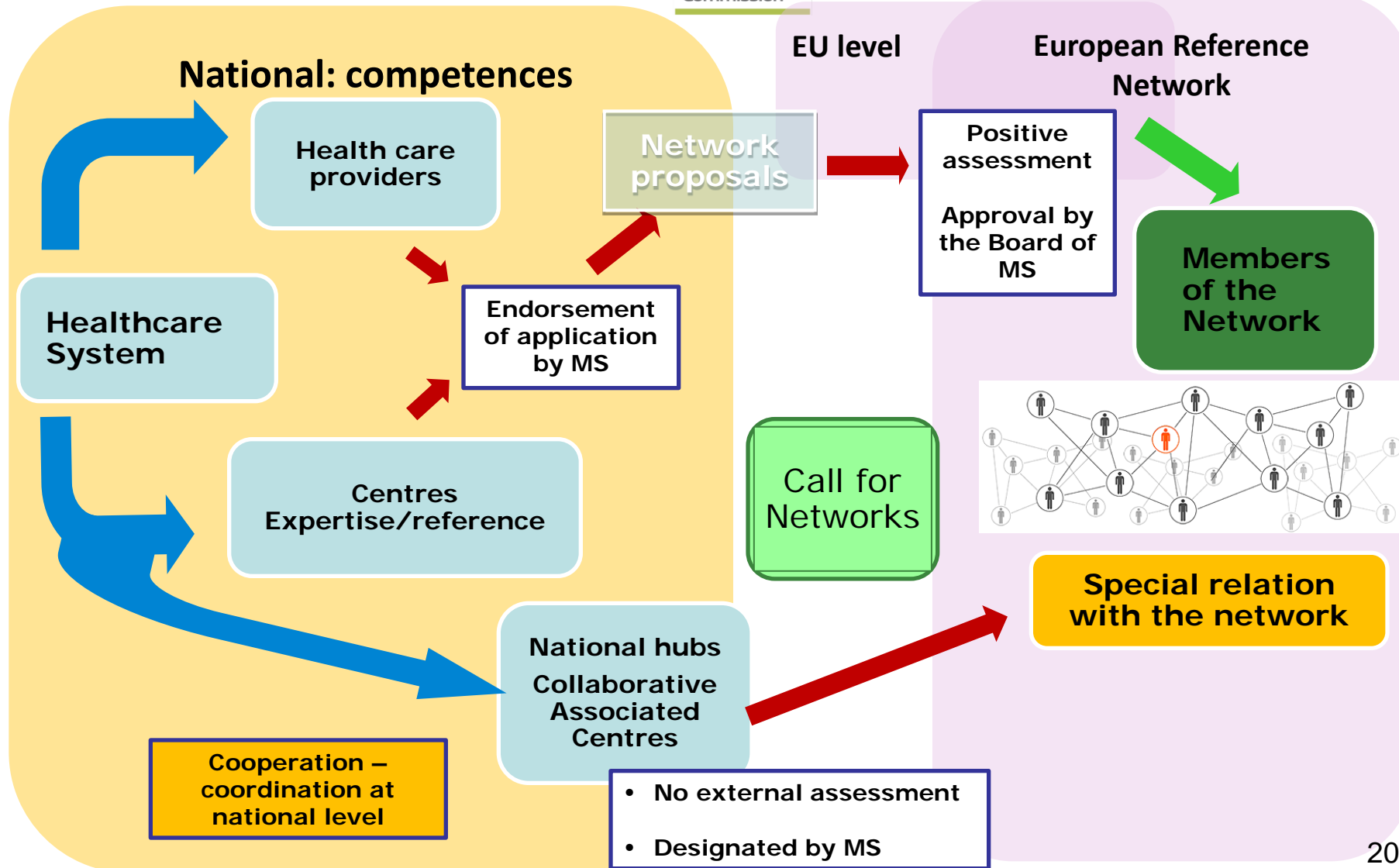


Independent Assessment Bodies

- solid background in assessment/certification Healthcare providers*
- Task: to perform the assessment of Networks proposals*
- Competitive Call: deadline for proposals 23 November 2015.*



Process & players



Timeline for ERNs



ERN timeline & milestones



2014



Entry into force
legal acts

2014-2015



Assessment
Manual

2015-2016



selection
independent
assessment
bodies

February 2016



Call for
Networks



2 quarter
2016

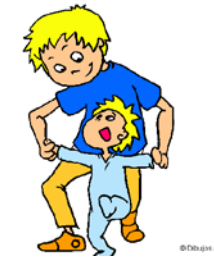


Assessment
proposals

3 quarter
2016



Establishment
of Networks



The road to ERNs



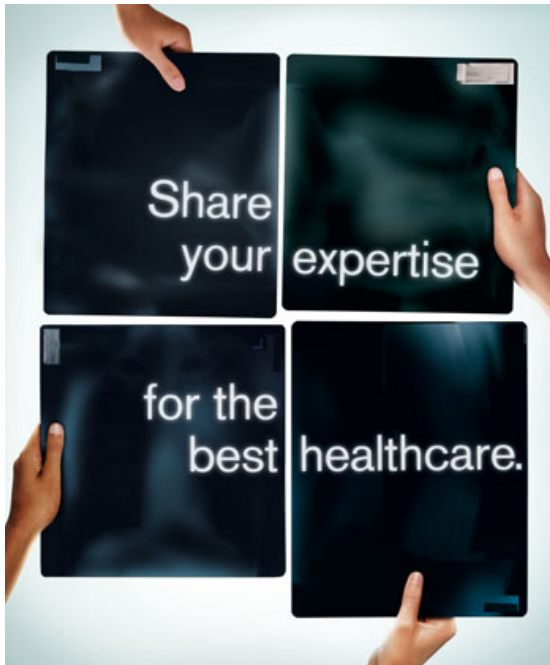
That's the purpose of the European Reference Networks and it's becoming a reality.

- *Share and enhance your expertise.*
- *Talk with your colleagues.*
- *Be ready to prepare a proposal and join a network.*
- *The European Commission will launch a call for Networks in 2016.*



**European
Reference
Networks**

Thank you!



Further information:

http://ec.europa.eu/health/ern/policy/index_en.htm