



European
Reference
Networks



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European Commission

European Reference Networks

***Directive of patients' rights in
cross-border healthcare***

From concept to reality...our state of readiness

- ⇒ *Background and legal base*
- ⇒ *The ERN model*
- ⇒ *State of play of the ERN call*
- ⇒ *The way forward*

The road to ERNs



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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**

The ERN model



- ⇒ *based in innovation*
- ⇒ *a new way of understanding healthcare provision and knowledge generation*

**THINK
OUTSIDE**



The bricks



Quality
High specialisation
Expertise
Knowledge
Research
Clinical care

The glue

Innovation
Trust
Solidarity
Generosity
Common project
eHealth



The goals & benefits

- ⇒ Better care & Diagnosis
- ⇒ Equal access
- ⇒ Reduce clinical variation
- ⇒ Develop standards
- ⇒ New treatments
- ⇒ Knowledge travels
- ⇒ Generate evidence
- ⇒ Better data
- ⇒ Capacity building
- ⇒ Economy of scale





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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

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**

Key features of the Networks

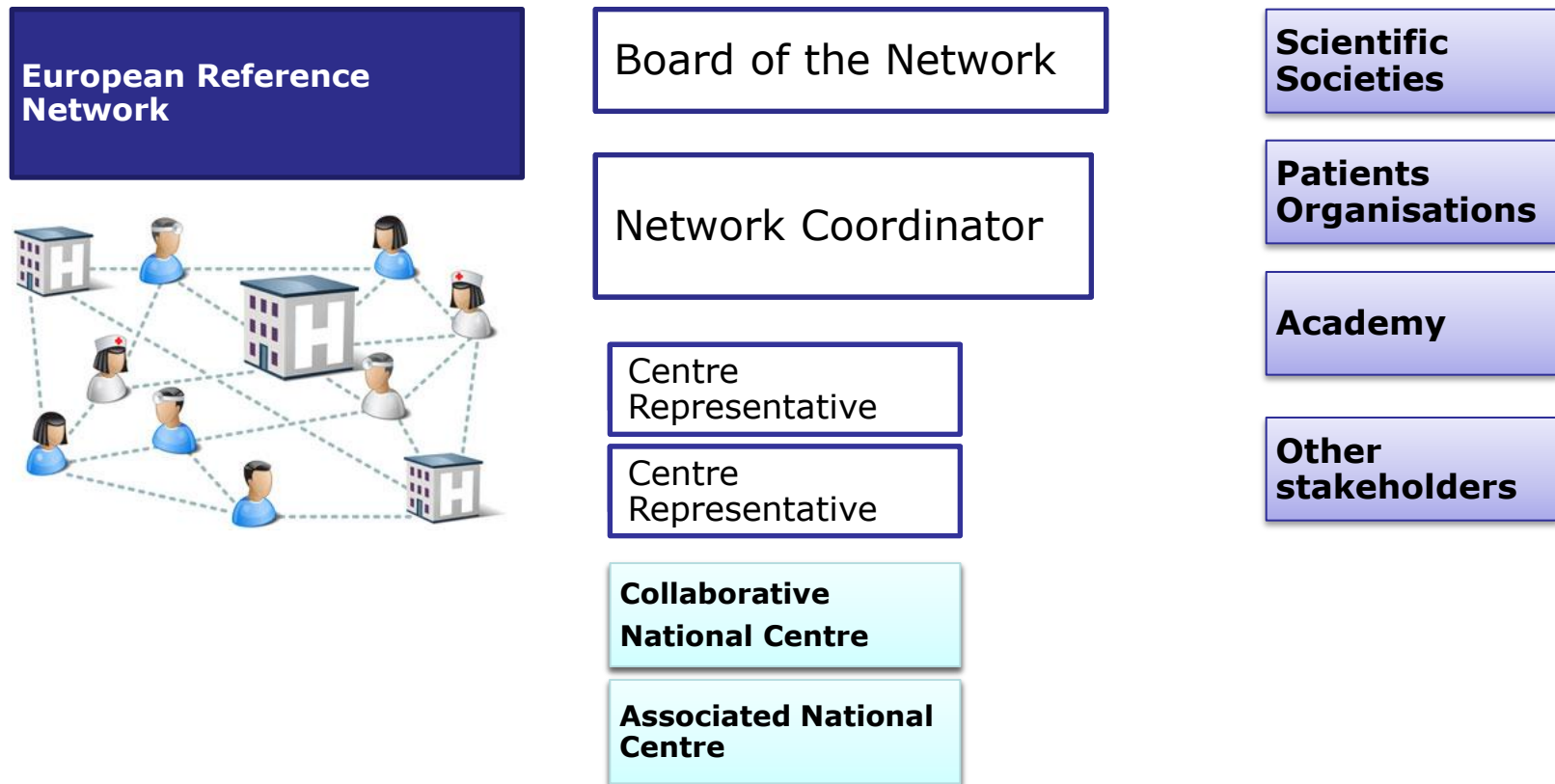
- ✓ *Patient centered and clinically lead*
- ✓ *10 Members in at least 8 Countries*
- ✓ *Strong independent (3rd party) assessment*
- ✓ *Fulfillment of Network and Members criteria*
- ✓ *Endorsement and approval by National Authorities (grouping and strategic value)*



Networks Governance

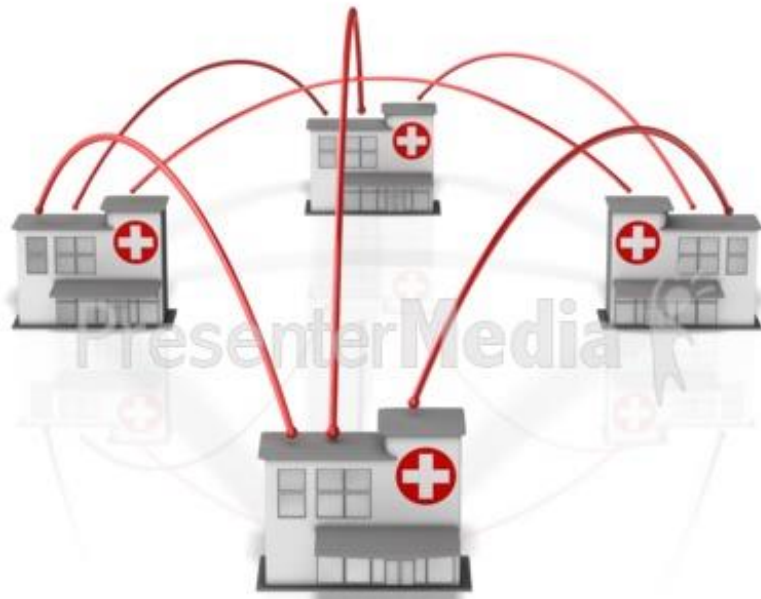


- ✓ **Transparent and effective** coordination & governance
- ✓ **Flexibility and key organizational features.**

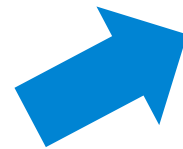




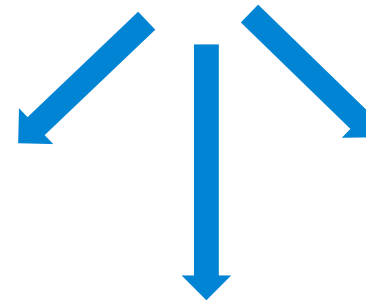
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Hospital

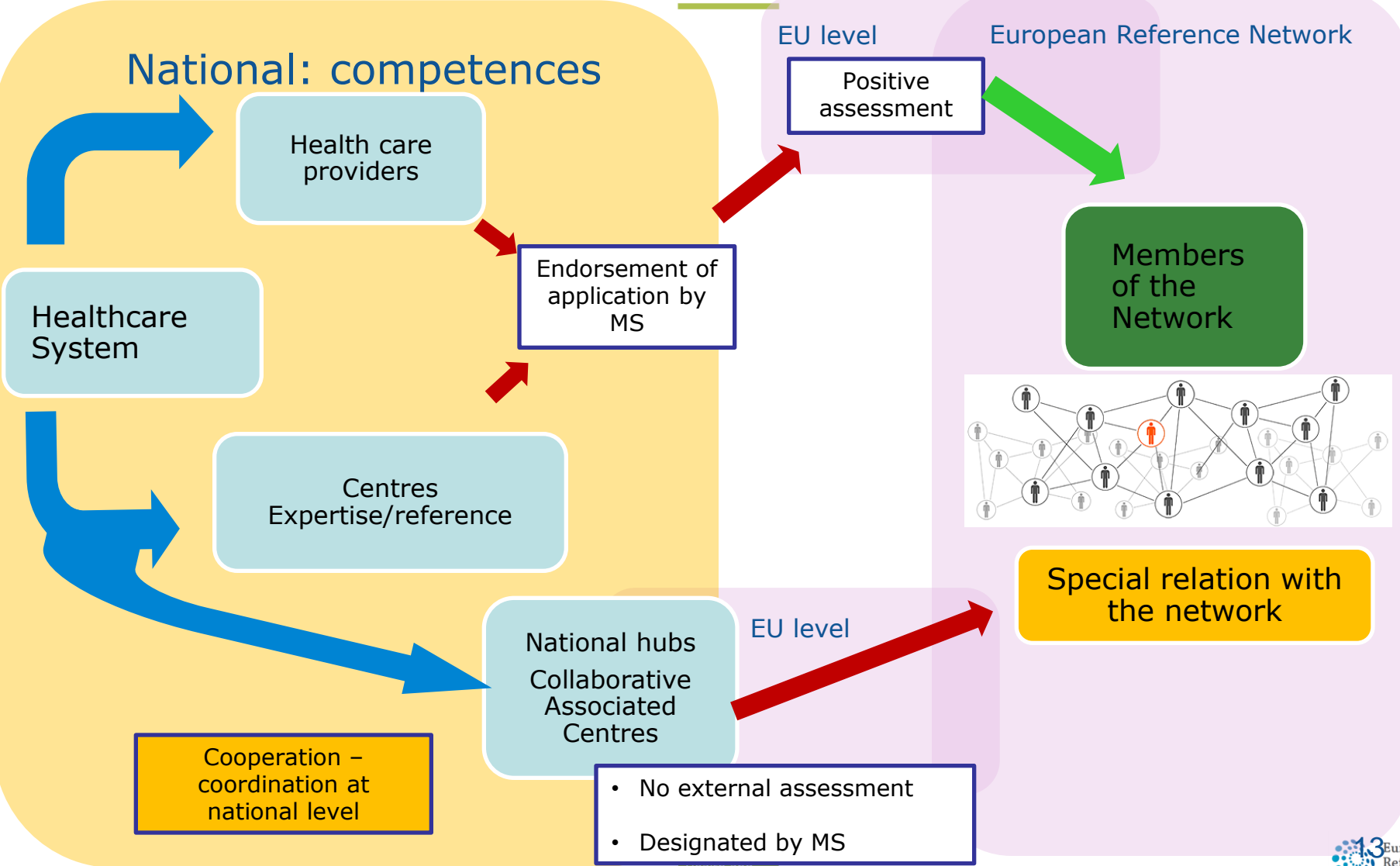


Experts units

Key role of Member States

- ✓ **Recognition of centers at national level.** (important differences) MS with systems in place (minority)
- ✓ **Endorsement** of applications
- ✓ **Board of Member States**
- ✓ **Approval** of Networks (once positively assessed)





Challenges and Successes



Integration

Breaking down the silos

- ⇒ *Separated groups,*
- ⇒ *Different pilot networks*
- ⇒ *Different specialities,*
- ⇒ *Lack of patient involvement,*
- ⇒ *Lack of common standards, guidelines, information...*

Building bridges



Thematic groups

Shared position of Commission Expert group on Rare Diseases, Member States and Patients associations

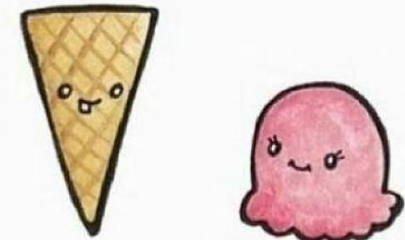
Rational: *Avoid fragmentation and overlapping*

Pros: *Strategic approach: manageable number of Networks*

All diseases will find a “home”

Integrative and seamless approach

Multidisciplinarity



better together

Contras: *complexity of governance, time to find agreements, different “ecosystem” & resistance to change*



Call for ERN

March - July 2016

Communication & awareness activities



European Commission

Info Day

Third European Union Action Programme in the field of Health - National Focal Points Meeting 18th March

ERN Info day
7th April



European Reference Networks

Share your expertise for the best healthcare

European Reference Networks Share, Care, Cure.

Anna Carta
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European Commission

European Reference Networks

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10.03.2016

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Update on the ERNs calls (1st and 2nd wave)

- ✓ **24** Network proposals
- ✓ **370** hospitals
- ✓ **960** expert units involved
- ✓ **26** Countries (25 EU Member States plus Norway)
- ✓ Covering **major challenges** in rare and complex diseases and conditions
- ✓ **20 thematic areas** included in the proposal of the Expert Group on Rare diseases (Gynaecology only partially)

Remember...

(3)



2013:

HAS DECIDED AS FOLLOWS:

Article 1



To apply for registration of European Reference Networks (ERN) logo as a trade mark in the EU, Norway, Iceland, Liechtenstein and Switzerland in the name of the European Union, and in relation to the abovementioned services.

Done at Brussels, 16.10.2013

*For the Commission
Paola Testori Coggi*

Sustainability and Support to the ERNs

⇒ Health Programme 2016

- Grants to support networking activities
- Patient registries projects
- Technical assistance assessment ERNs applications
- 3rd ERN Conference (March 2017) Kick off meeting ERNs

⇒ Connecting European Facilities (2015-2017)

- IT Platform



Research Programme H2020 and potential future actions on Rare Diseases Research.



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Join Action on Rare Diseases:



ERN tentative timeline & milestones



July 2016



Call for Networks

July-November 2016



Assessment proposals

December 2016



Approval ERN by Board MS

November 2016 – March 2017



Grant evaluation

March 2017



3rd ERN Conference & Kickoff meeting ERNs



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Thank you!



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



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European Reference Networks

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

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

Share and enhance your expertise. Talk with your colleagues. Join a **Network proposal** in early 2015.

More information at ec.europa.eu/join-ern

Share. Care. Cure.

Supported by the