Past, presence and future of Centres of Expertise and European Reference networks

First Conference on European Reference Networks, The Square, Mont des Arts, Brussels, 23.06.2014

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Legislative Framework

Concept of „Centres of Expertises“

- Council recommendation 2009
- CoE (> ERN); national plans / strategies
- „Soft law“ (J. F. Ryan)
  (Acting Director Public Health Directorate)

Concept of „European Reference Networks“

- Cross-border healthcare directive 2011
- ERN (> CoE)
- „Hard-core law“
Concept of „Centres of Expertises“
- Council recommendation 2009
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Concept of „European Reference Networks“
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### Past

**CoE and ERN Concepts**
- **Member States**
- **European Commission**
- **Committees**
  - High Level Group
  - Task Force on Rare Diseases
  - EUCERD
  - CBHD Expert Group

#### Timeline perspective

1. **First Conference on European Reference Networks**, Brussels, 23.06.2014
2. **Past, Presence and Future of CoE and ERN** - T. Voigtlander, Vienna, Austria

<table>
<thead>
<tr>
<th>Timeline</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Past</strong></td>
<td>• Report High Level Group (including&lt;br&gt;Report „Overview of current Centres of Reference on RD“ (2005))&lt;br&gt;• Recommendations: “Quality Criteria for&lt;br&gt;Forum for consultation and advice from the MS to the Commission regarding the elaboration of the delegated (and implementing) decision(s) of the CBHD (2012-2013)**</td>
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</tbody>
</table>
Transitional State

Timeline perspective

Past

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• Forum for consultation and advice from the MS to the Commission regarding the elaboration of the delegated (and implementing) decision(s) of the CBHD (2012-2013)
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Timeline perspective
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EU legislation - State of Play
• Cross-border healthcare directive
• Accompanying legal decisions

Legal framework for ERN and Centres:
• Commission Delegated Decision setting out criteria and conditions for ERN and healthcare providers (May 2014)
• Commission Implementing Decision setting out criteria for establishing and evaluating ERN and their Members and for facilitating exchange of information and expertise (May 2014)
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Timeline perspective

Past

CoE: • Responsibility of the MS
ERN: • Members of the ERN (centres): responsibility of MS
  • Coordination and core activities: responsibility?
  • CBHD does not provide solutions for continuous financial support
  • Solutions in the future?
  • How to bridge the gap?

Future

Implementations Procedure
• Establishment of ERNs and CoE
• Sustainability of ERNs and CoE
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Transitional State

Timeline perspective

Past

Present

Future

Feasibility perspective

Theory

CoE and ERN Concepts
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Transitional State

Timeline perspective

Past

Examples:

• DYSCERNE (2007 – 2009)
• ECORN-CF (2007 – 2010)
• PAAIR (2008 – 2011)

Future

Feasibility perspective

Theory

- Differing types of networks:
  a) Research networks
  b) Public health networks
- Evaluation / Lessons learned
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Transitional State

Examples:
• ExPO-r-NeT (2014 – 2017)
• E-PILEPSY (2014 – 2017)
• e-ENERCA (2013 – 2016)

Real life ERNs
• 2nd generation European Pilot Reference Networks of “CoE”
• Designation experience
• Empirical operating experience

Timeline perspective
Feasibility perspective
Theory
Practice
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Contextual Referential Statement

Timeline perspective

Feasibility perspective

Past

Roundtable (T. Voigtländer)

Session A-2 (Centres of Expertise)

Presence

Session B-2 (Accreditation and Evaluation of CoE)

Session A-3 (Pilot Networks)

Future

Practice

Theory
Thank you very much for your attention.