



European
Reference
Networks

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

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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**“

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Concept of „European Reference Networks“

- Cross-border healthcare directive 2011
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Timeline p Past

CoE and ERN

- Member States
- European Commission
- Committee of Ministers
 - High Level Group
 - Task Force
 - EUCERD
 - CBHD Expert Group

- Report High Level Group (including
- Report „Overview of current Centres of Reference on RD“ (2005)
- Recommendations: “Quality Criteria for
- 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)

Transitional State

Timeline perspective

Past

- **CoE and ERN**
 - **Member States**
 - **European Commission**
 - **Committee of the Regions**
 - **High Level Group of Experts**
 - **Task Force**
 - **EUCERD**
 - **CBHD Expert Group**
- **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)**

Timeline p

Past

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)

EU legislation

- Cross-border healthcare directive
- Accompanying legal decisions

Timeline p

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 ?**

Implementing procedure

- **Establishment of ERNs and CoE**
- **Sustainability of ERNs and CoE**

Future

Transitional State

Timeline perspective

Feasibility perspective

Past

Theory

Present

Future

CoE and ERN Concepts

- Member States
- European Commission
- Committees
 - High Level Group
 - Task Force on Rare Diseases
 - EUCERD
 - CBHD Expert Group

Transitional State

Timeline perspective

Past

Feasibility perspective

Theory

Examples:

Examples:

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

Future

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

Transitional State

Examples:

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

perspective

theory

Present

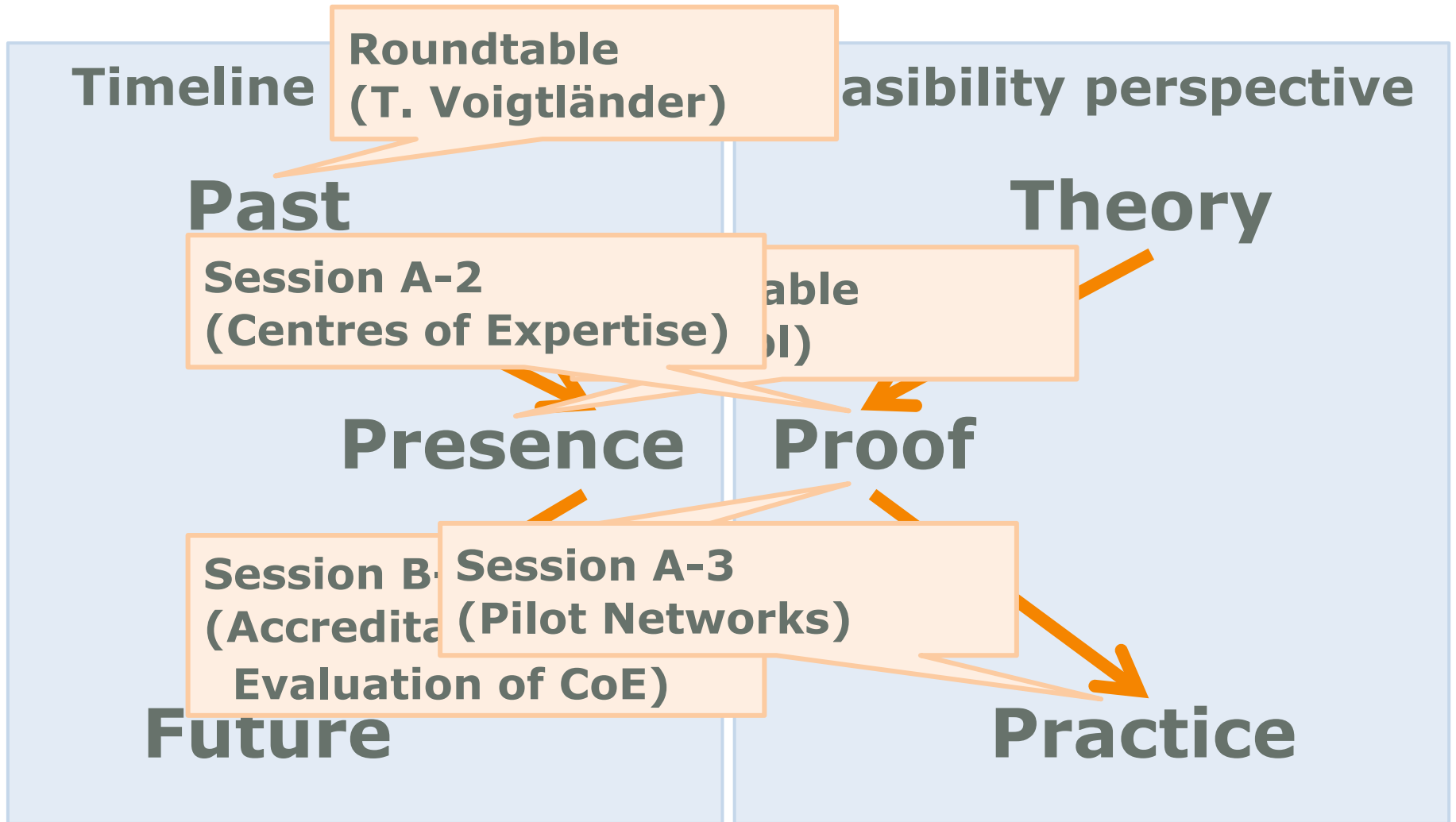
Real life ERNs

- 2nd generation European Pilot Reference Networks of “CoE”
- Designation experience
- Empirical operating experience

Future

Practice

Context, Content and Contribution



Context of the Conference

Timeline perspective

Feasibility perspective

**Thank you very much
for your
attention**



Future

Practice