

European Reference Networks

Issues addressed and key support developments of the Member States to the networks

Till Voigtländer

4th Conference on European Reference Networks: “ERNs in action”, Charlemagne Building, Brussels, 21–22/11/2018

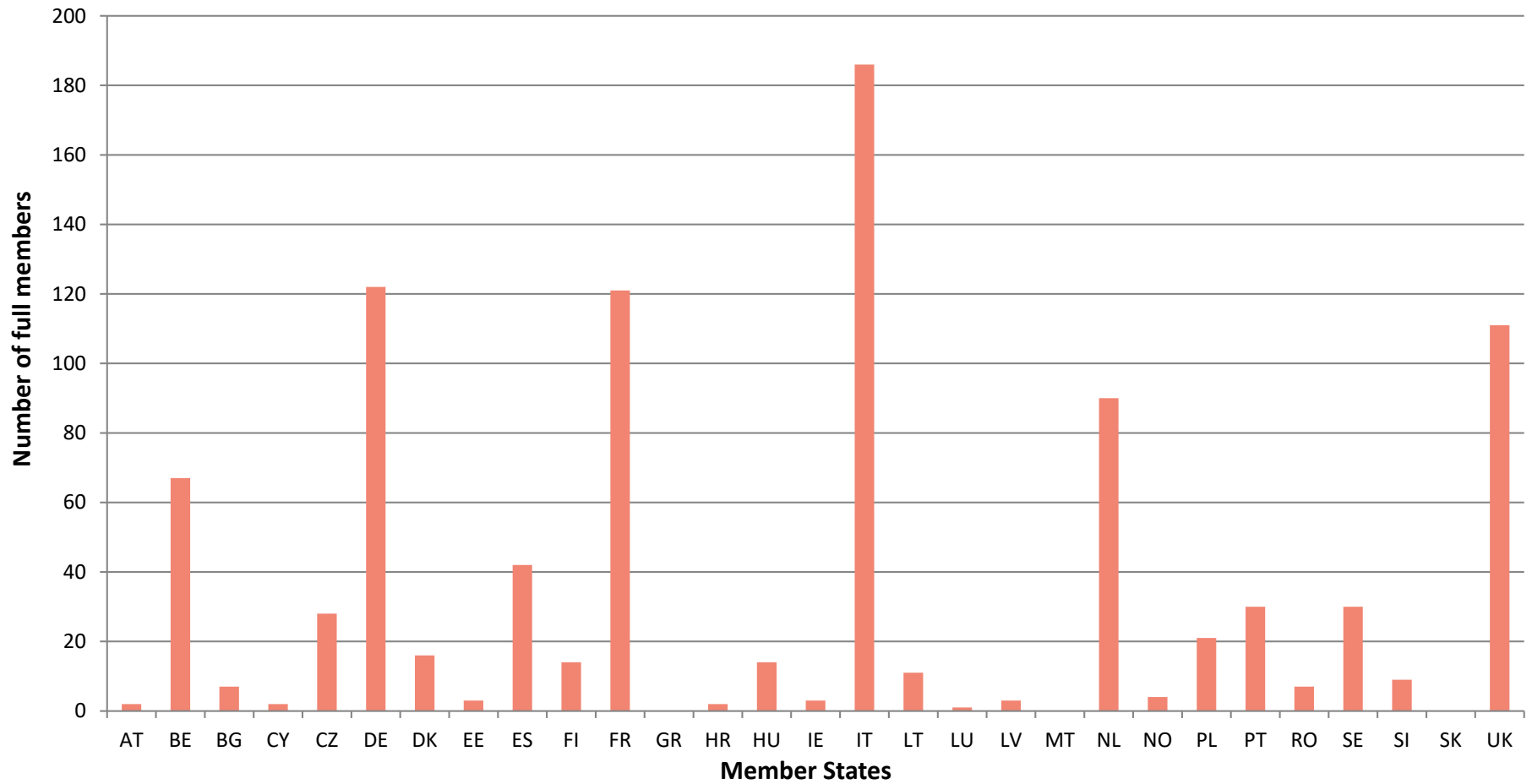
Contents

- » Specifying the term “Issues addressed”
- » What are main issues to be addressed
- » How to address these issues
- » Where are we right now

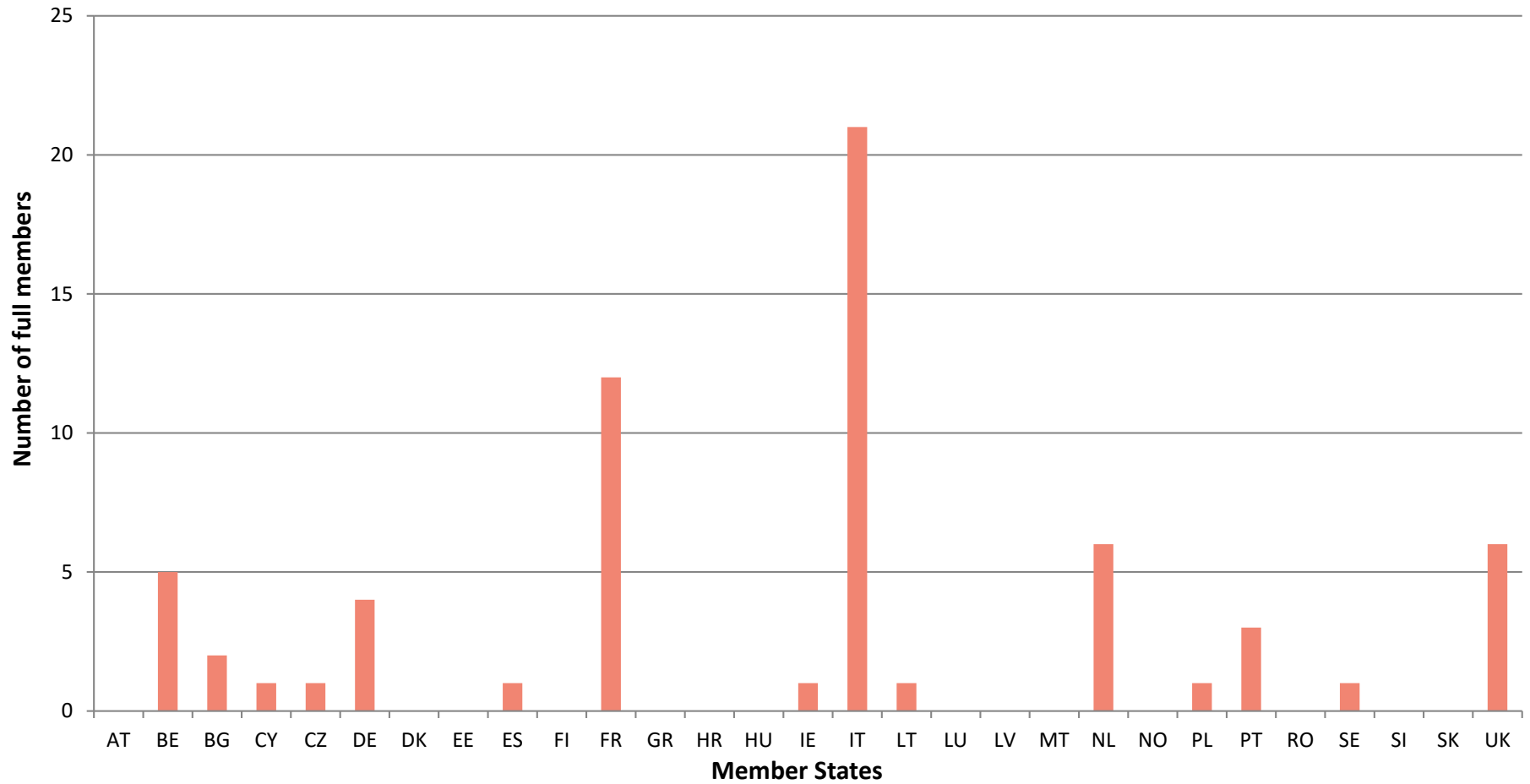
Specifying the term “Issues addressed”

- » Issues (successfully) addressed in the past
- » Issues that are currently addressed
- » Issues addressed up to the level of an intermediate solution but that need further attention
- » Issues that need to be addressed in the future

Member State representation across all ERNs



Member State representation within a given ERN



What are main issues to be addressed (1)

- » Imbalanced Member State representation across all ERNs (0–186 full members)
- » Imbalanced Member State representation within single ERNs (for instance 21 out of 66 members from one MS)
- » Development of steering elements to evaluate, monitor and support the performance of the networks
- » Ethical aspects in the relation and cooperation with third parties (industry, other stakeholders)
- » Seamless integration of ERNs and their members into the national health care systems

What are main issues to be addressed (2)

- » Gaps in the coverage of disease groups within ERNs
- » Funding aspects

How to address these issues

» Tools

- » Establishment, refinement and better interaction of **governance structures**
 - » Board of Member States on ERN (BoMS; legal body)
 - » ERN Coordinators Group (ERN-CG; ERN initiative)
- » Establishment of **working groups** (selection)
 - » WG on “Affiliated partners” (BoMS)
 - » WG on “ERN Continuous Monitoring and Quality Improvement System” (BoMS & ERN-CG)
 - » WG on “Integration of ERNs into national health systems” (BoMS & ERN-CG)
 - » WG on “Ethical and Legal issues, relation with Stakeholders” (BoMS & ERN-CG)
- » Development of **concepts** and **instruments**

Where a

» Imbalance
all ERN

- WG on “Affiliated partners”
 - Detailed concept of
 - Associated National Centres (ANC)
Coordination hubs
 - First roll-out between 12/2018 and 04/2019 (approx.)

- MS-based identification of new candidates for full membership
 - Inclusion based on the timeline of the next call and the assessment of the candidates

Where a

» Imbalance
all ERN

- WG on “Affiliated partners”
 - Detailed concept of
 - Associated National Centres (ANC)
Coordination hubs

» Imbalance
single
from c

- MS-based identification of new candidates for full membership

» Develop
monito
netwo

- WG on “ERN Monitoring”
 - Stepwise development of indicators
 - Development of an IT-based “Continuous Monitoring and Quality Improvement System”
- Feedback to BoMS and individual MS concerned

Where are we – trying to address the issues (3)

- » Imbalanced Member State representation across all ERNs (0–186 full members)
- » Imbalanced Member State representation within single
from c
 - WG on “Ethical and legal issues”
 - Further development of the BoMS statement on “ERNs and Industry”
- » Develop
monitor and support the performance of the networks
- » Ethical aspects in the relation and cooperation with third parties (industry, other stakeholders)

Where are we – trying to address the issues (4)

- » Imbalanced Member State representation across all ERNs (0–186 full members)
- » Imbalanced representation of Member States in single ERNs (e.g. 28 from one Member State)
- » Development of a common framework for monitoring and evaluation of ERNs
- » Ethical and legal issues (involvement of third parties (industry, other stakeholders))
- » Seamless integration of ERNs and their members into the national health care systems

- WG on “Integration of ERNs in national health systems”
 - 28 Member States = 28 different healthcare systems
 - Need for “28 tailored solutions”
 - Need to involve several (different) stakeholders in each Member State

Where are we – trying to address the issues (4)

- » Imbalanced Member State representation across all ERNs (0–186 full members)
- » Imbalanced representation of Member States in single ERNs (e.g. 28 from one Member State)
- » Development of a common framework for monitoring and evaluation of ERNs
- » Ethical and legal issues (involvement of third parties (industry, other stakeholders))
- » Seamless integration of ERNs and their members into the national health care systems

- WG on “Integration of ERNs in national health systems”
 - 28 Member States = 28 different healthcare systems
 - Need for “28 tailored solutions”
 - Need to involve several (different) stakeholders in each Member State

Where are we – trying to address the issues (5)



» Gaps in the coverage of disease groups within ERNs

- 
- ERN–CG analysis
 - Further calls for members in ERNs
 - Support by Member States in identifying appropriate candidates

Where are

- EC/MS funding
 - 1 million EURO/ERN/5 years cycle
- » Gaps in the ERNs
- » Funding aspects
 - Funding strategies have to be decided between the EC, the European Parliament and the MS
 - Multiannual Financial Framework (MFF)
- » ERN cooperation
- » ERN activities
 - Participation of industry and other stakeholders
- » Registries
- » Guidelines
- » Research
- » CPMS panels

Where are we – trying to address the issues (6)

- » Gaps in the ERNs
 - » Funding aspects
 - » ERN cooperation
 - » ERN activities
 - » Registries
 - » Guideline development
 - » Research
 - » CPMS panels
- EC/MS funding instruments
 - European Joint Programme Co-Fund on Rare Diseases (EJP; 2019–2024)
 - Innovative Medicines Initiative (2018–2023)
 - Long-term strategy ?
- New ideas and concepts are needed
- 
- 

Summary

- » Specifying the term “Issues addressed”
- » What are main issues to be addressed
- » How to address these issues
- » Where are we right now

ERN-Konzept in der Computertomographie

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

till.voigtlaender@meduniwien.ac.at

