

Bridging the gaps and creating opportunities

ERNs state of play and lessons learned:
Member States' perspective

1st Plenary Session

Till Voigtländer

4th Hospital Managers' meeting, Brussels, On-line event,
21-22 October 2021

Some thoughts on “Lessons learned”

- » “Lessons learned” – what does the phrasing imply?
- » In general terms, it means:
 - » We performed something in the past
 - » Now, for instance years later, we look back to the start and evaluate what worked and what did not work
- » In short, we face **challenges** – and we want or have to act

Some thoughts on “Lessons learned”

» Our options to act:

Do more

» We have to do more

Do better

» We have to do better

Do it different

» We have to do it different

» Any combination of the above

A plea for ERNs

- » Reasons for the “Lessons learned” situation
 - » ERNs are “a first time ever” in history, in Europe and in the world
 - » There is no model for this endeavour in the past, instead, ERNs might once serve as a role model for other regions
 - » The concept of ERNs has **intrinsic challenges by nature**

A plea for ERNs

» ERN concept caught between conflicting principles

» **Common vision**

» CBHD-EG; EUCERD

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» **Principle of subsidiarity**

» 27+1 different National healthcare systems

» Centralized

» Federal

» Regional

» Mixed

» 25 different selection strategies of HCPs

» 25 different endorsement strategies for HCPs

A plea for ERNs

» ERN concept caught between conflicting principles

» **Internal system speed**

- » Relatively slow speed in analysis, discussion, decision making and adoption processes on the EC–MS level

» **External pace**

- » Rapid pace in technological developments (e.g. IT area; eHealth data; augmented intelligence)

A plea for ERNs

» ERN concept caught between conflicting principles

Key messages:

- » Stepwise improvements with the help of “Lessons learned”–insights are a good and not a bad thing
- » Not every delay in progress is a bad thing
- » ERNs are still “Work in progress”

Lessons learned

» Areas

- » Structural and organizational level
 - » Size and disease coverage of ERNs
 - » ERN integration into national health systems
- » IT level
 - » CPMS
 - » Registries
 - » Coding
- » Evaluation level
 - » Monitoring
- » Communication between key actors

Lessons learned

- » Areas
 - » Structural and organizational level
 - » Size and disease coverage of ERNs
 - » ERN integration into national health systems
 - » IT level
 - » CPMS
 - » Registries
 - » Coding
 - » Evaluation level
 - » Monitoring
 - » Communication between key actors

Structural / organizational level

» Size and disease coverage of ERNs

» Expected / projected situation 2016
(CBHD-EG: 2012-2013; BoMS: 2015-2016)

» Key parameters defining ERNs:

» 10 (full) members

» 8 different European Member States

» First hopes (before “matchmaker tool”)

» 8-10 applications

» 5 mature applications

» ~ 75-100 members

Structural / organizational level

» Size and disease coverage of ERNs

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Structural /organizational level

» Size and disease coverage

Highly attractive model

» Current Situation

No promise for any money
for any HCP

» 24 ERNs

» First call full members: 956 FM

» First inclusion at Still no full disease coverage

» Second call full members ~ 630 FM

» In total 1700–1800

Endangering operability

Endangering sustainability

Structural level

Do it different

» Size

One option in discussion:

»

» Creation of **National Reference Networks** reflecting ERNs on a national level

» Defining a number of **node centres** within each NRN

» These node centres link NRNs and ERNs and **constitute future members** of the respective ERNs

» The other NRN centres need to have a different link to the ERNs, too

Project JA on integration (from 2022)

Structural / organizational level

» Integration of ERNs in national health systems

» Key promises of ERNs

Do better

» Facilitated **mobility of expertise**

(Data traveling rather than patient mobility)

Do better

» **Faster** and state of the art **diagnosis**

Do better

» **Earlier** and **high quality healthcare**

» **Better patient pathways** in national healthcare systems and towards ERNs

Do better

Structural / organizational level

- » **Interoperability**
 - » Improving virtual consultations (ERNs):
 - » Recent improvements in the Clinical patient management system (CPMS)
 - » Development of a new, user-friendly, modular, customizable CPMS in 2023

» **Faster and state of the art diagnosis**

Do better

Fostering national integration:

- » Working group on integration (since 2018)
- » European JA on integration (from 2022)

Do better

IT aspects

- » Clinical patient management system (CPMS)
 - » Virtual panels of experts discussing submitted patient cases
 - » Feedbacks from experts over the time
 - » Complicated to use
 - » Inflexible and monolithic structure
 - » Inappropriate tools for uploading additional data (images, EEG, etc.)
 - » No or very restricted customization options for individual ERNs
 - » **Restrictions on the national level** (access, data transfer)

IT aspects

Do better

» Clinical patient management system (CPMS)

- » Recent improvements in the (interim) Clinical patient management system (CPMS)
- » Development of a new, user-friendly, modular, customizable CPMS in 2023
- » National level needs still to be addressed:
 - » 27+1 different MS with different regulations (central, local)
 - » Different stakeholders responsible
 - » Support options from hospital level?

Evaluation level

» Monitoring and evaluation of ERNs and HCPs

» History

- » One dedicated evaluation process every 5 years
- » Limited technical assessment capacities after 1st call (number of applicants 957)
- » Shift to **continuous monitoring idea/principle**

Do it different (2017)

Evaluation level

- » Monitoring and evaluation of ERNs and HCPs
 - » History
 - » One dedicated evaluation process after 5 years
 - » Limited technical assessment capacities after 1st call (number of applicants 957)
 - » Shift to continuous monitoring idea/principle
 - » WG on monitoring
 - » Definition of indicators and first tools
 - » Periodic self-assessment
 - » Risk of over-burdening ERNs / HCPs with data collection

Do better

Do it different

Evaluation level

» Monitoring and evaluation of ERNs and HCPs

»

AMEQUIS project (2020–2021)

» Integrated **A**ssessment, **M**onitoring, **E**valuation and **Q**uality Improvement System

» Combines the different data sources, assessment steps and activities of ERNs and HCPs

»

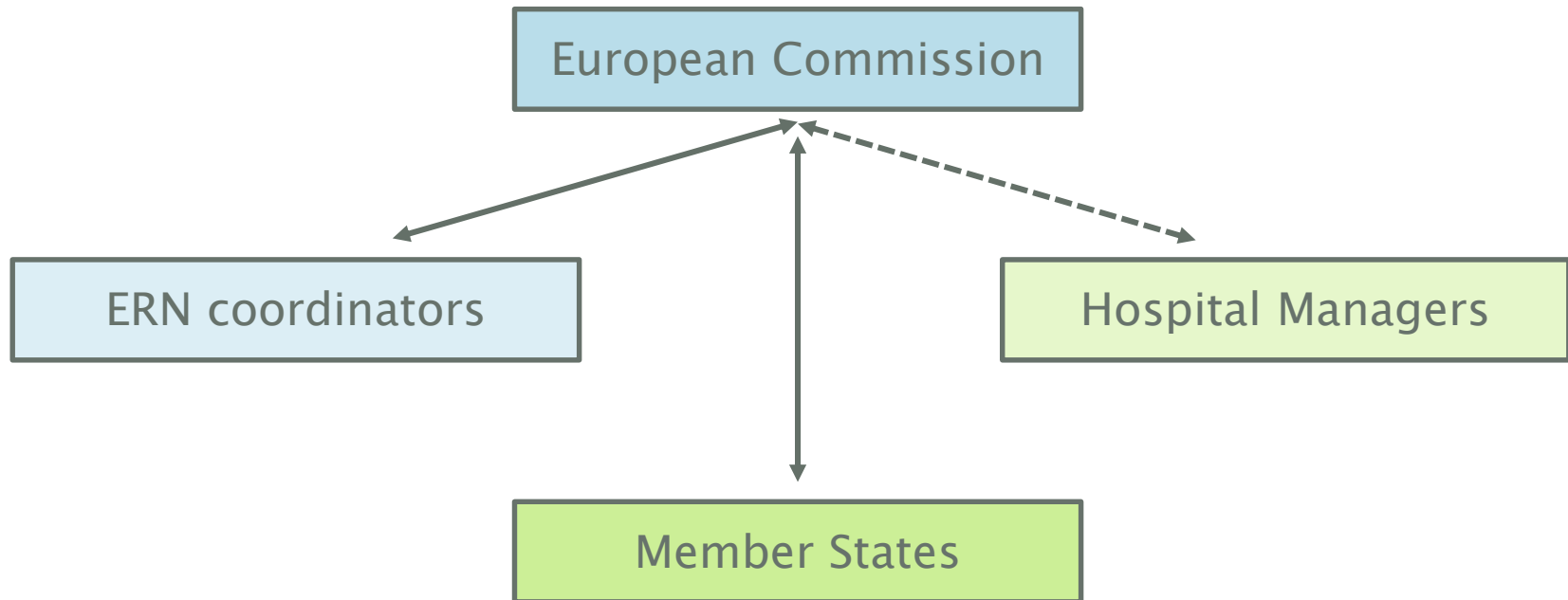
» Integrates quality improvement cycles

» Includes at some point some degree of automation of data collection

collection

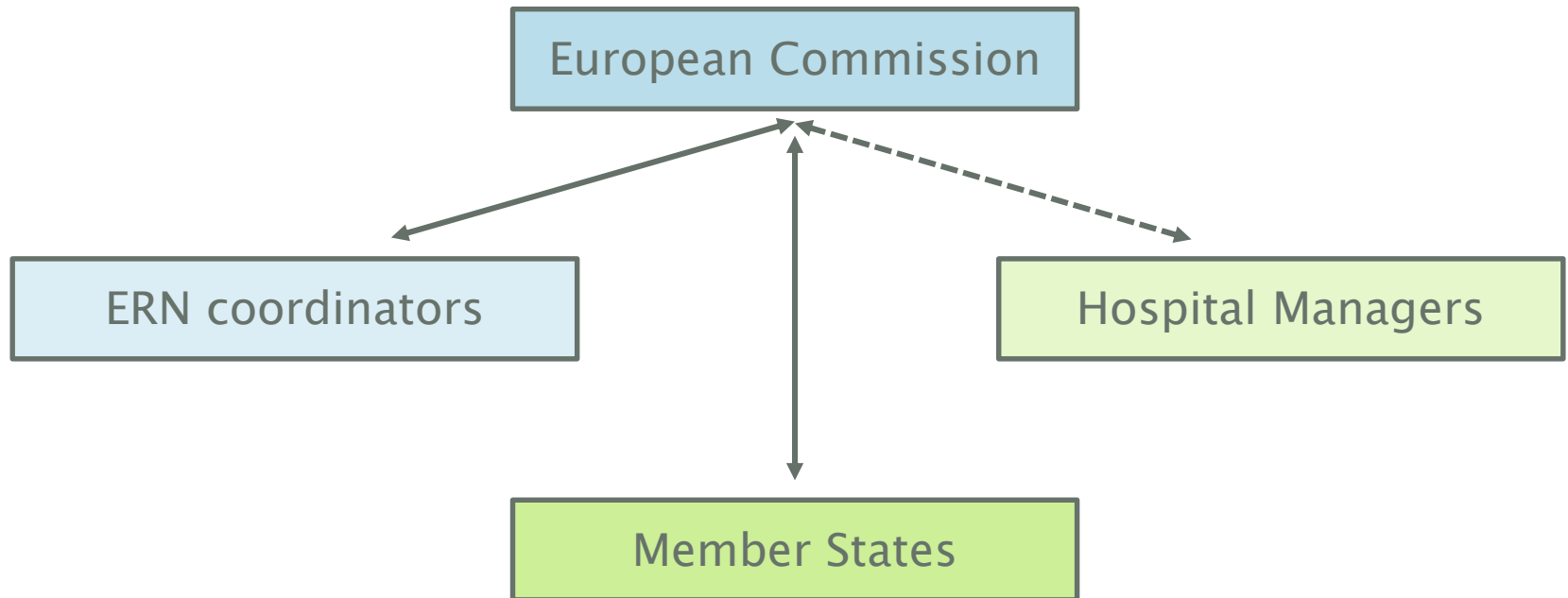
Communication between key actors

- » Key actors and main ways of communication:
 - » Current situation:



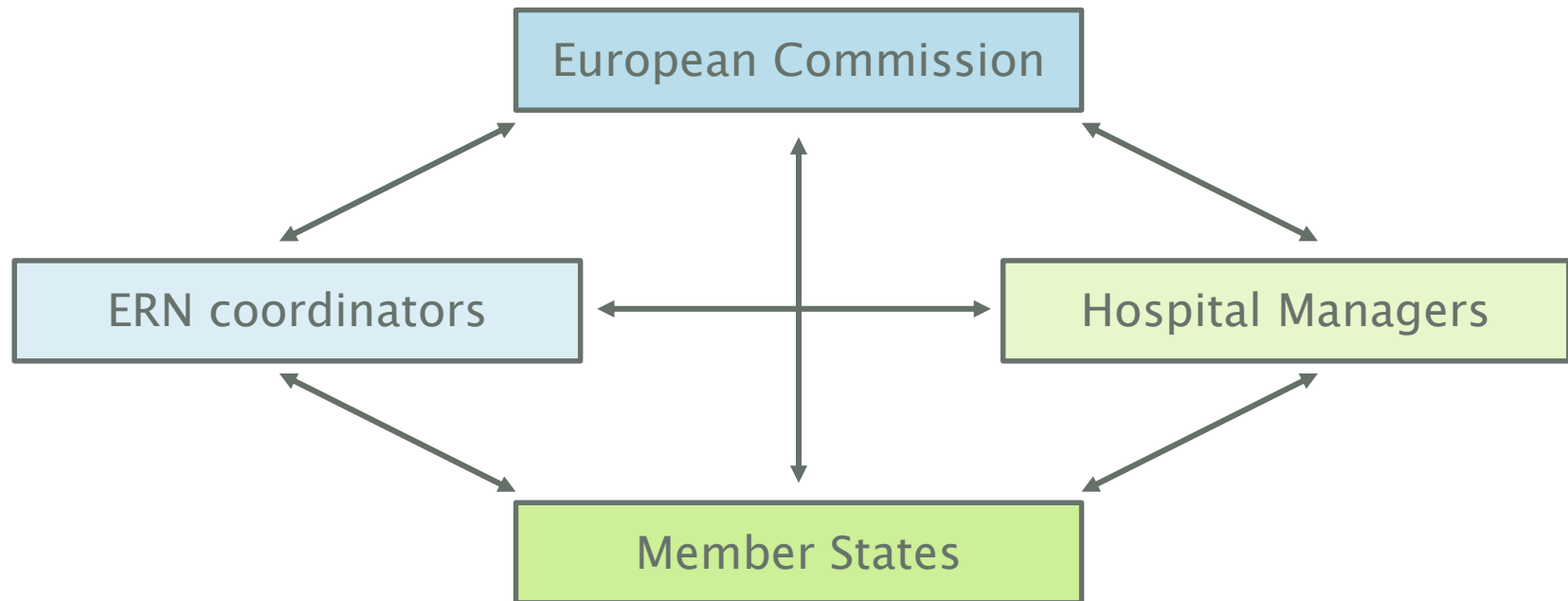
Communication between key actors

- » Key actors and main ways of communication:
 - » Future option?



Communication between key actors

- » Key actors and main ways of communication:
 - » Future option?



Summary

» Lessons learned – Areas

Please keep in mind:

ERNs are **“Work in progress”**

We are on a **common journey**
and **share many tasks**

» Monitoring

» Communication between key actors

ERN-Konzept in der Computertomographie

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

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