

Four years of ERNs: lessons learned for the future

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4TH ERN HOSPITAL MANAGERS MEETING



Observatory scoping study

- Rapid review of literature and semi-structured expert interviews
- Hospital managers participating in ERNs, medical specialists, network coordinators, European Commission policy officers
- Summer 2020
- ERN activities, coordination and structure, cost elements and outcomes, perceptions of opportunities and challenges in the operation and management of ERNs, potential expansion
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Notable activities

- **Clinical guidelines**
- Care pathways
- **Educational activities (face to face and digital)**
- **Research activities (studies, publications, registries, surveys?)**
 - Funding for research comes from different sources on top of EC support grants, such as national/international grants, industry, governments
- Knowledge pooling

European Reference Network:
Clinical Practice Guidelines
And Clinical Decision
Support Tools

Methodological Handbooks & Toolkit
for Clinical Practice Guidelines and
Clinical Decision Support Tools for Rare
or Low Prevalence and Complex Diseases
Introductory document



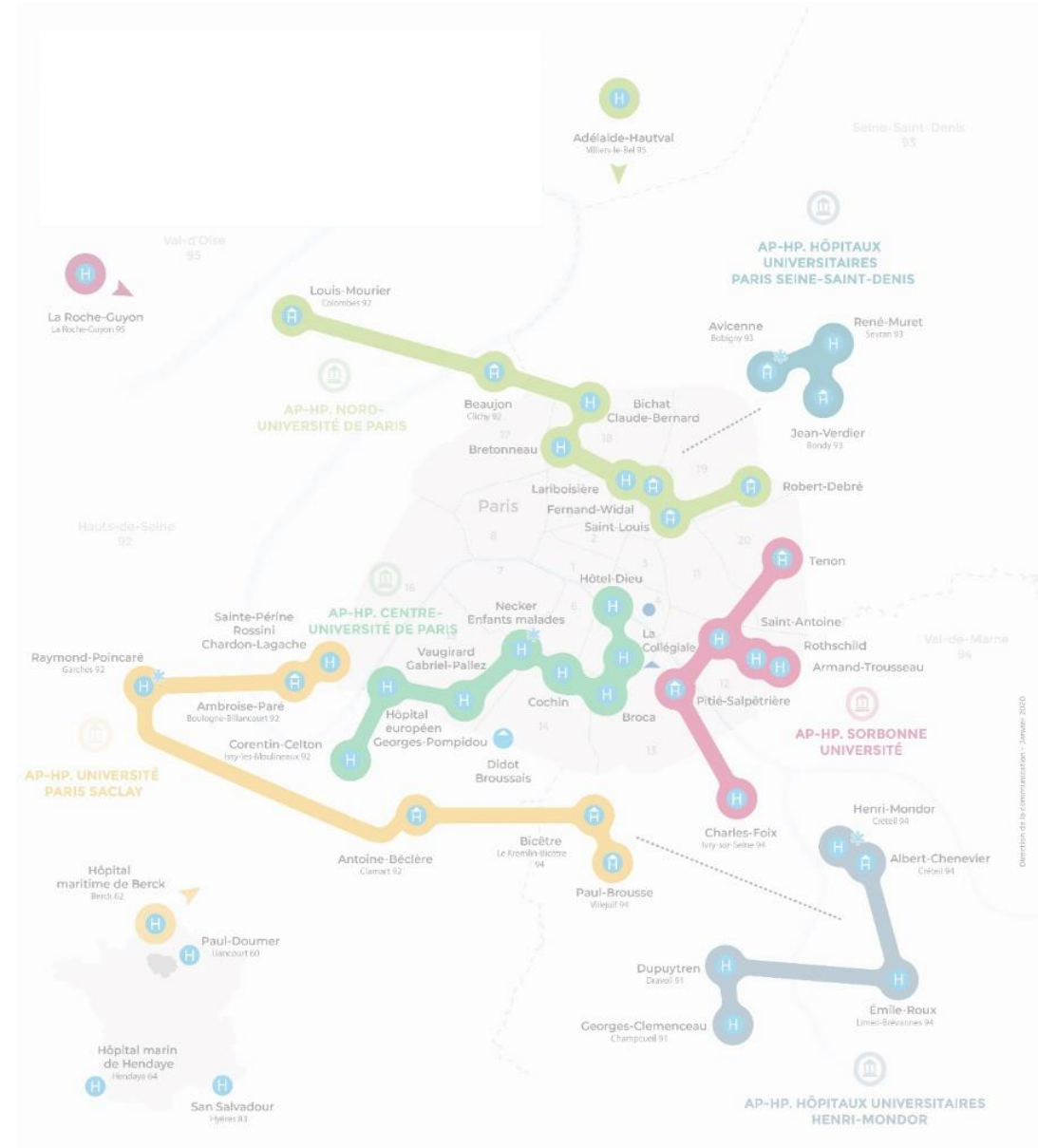
Coordination issues

- Severe administrative burden for network coordinators
- Different levels of governance (Board, executive board, working groups)
- Freedom of organization leads to considerable differences
- How many members are too many?
- Over/underrepresentation of countries, regional imbalance
- Not all conditions receive same attention



Integration into national health systems

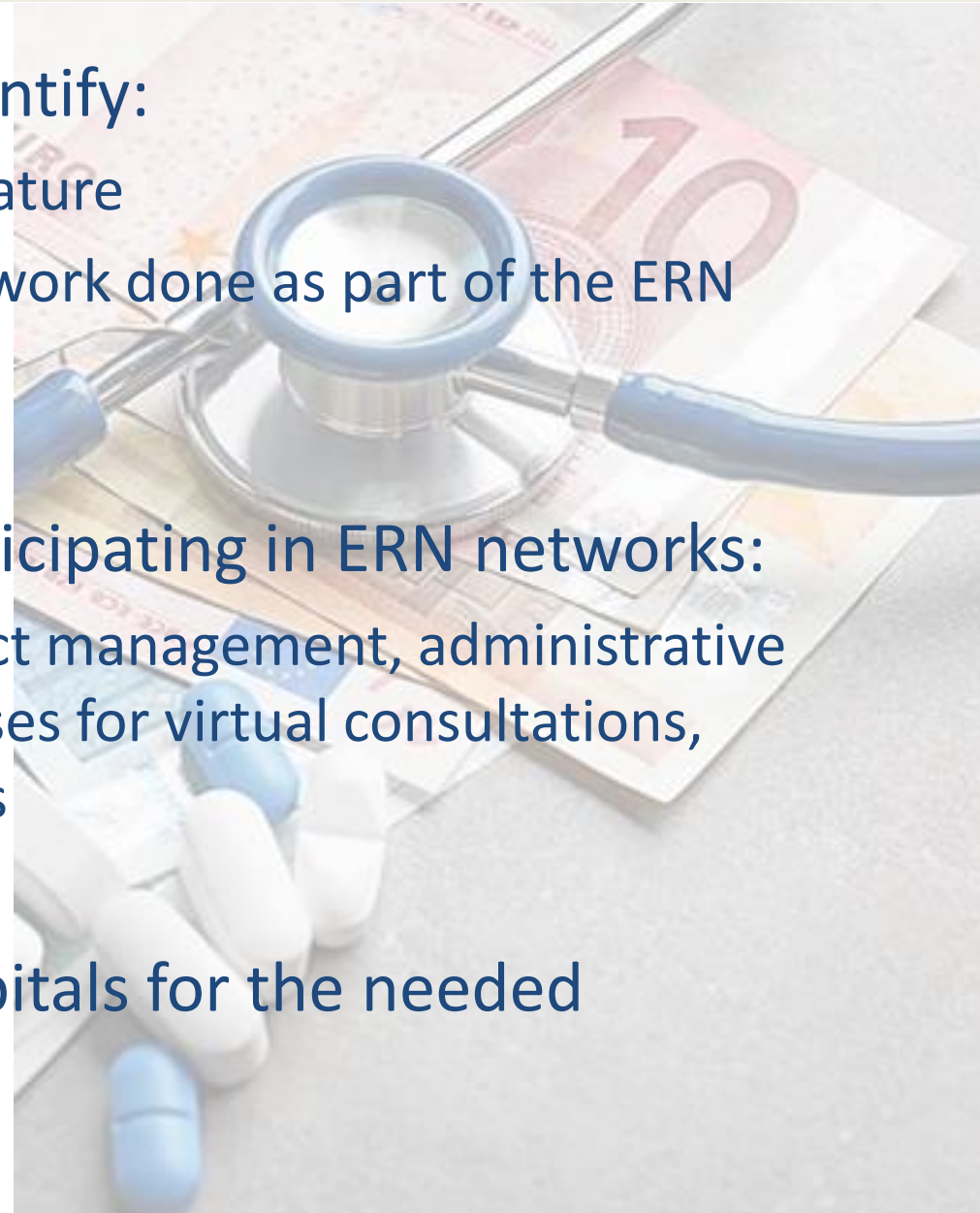
- Paramount for better coordination
- Could add but also save costs
- Need to demonstrate added value of ERNs clearly
- Room for cross-country learning





Costs and financing

- Costs of ERN system difficult to quantify:
 - Multi-stakeholder and cross-border nature
 - clinicians in hospitals rarely separate work done as part of the ERN from day-to-day work
- Staff time is the biggest cost of participating in ERN networks:
 - time for the coordination roles, project management, administrative roles, clinical expertise for triaging cases for virtual consultations, virtual panels, clinical time for experts
- Reliance on the support of the hospitals for the needed resources (such as staff time)



Costs and financing (II)

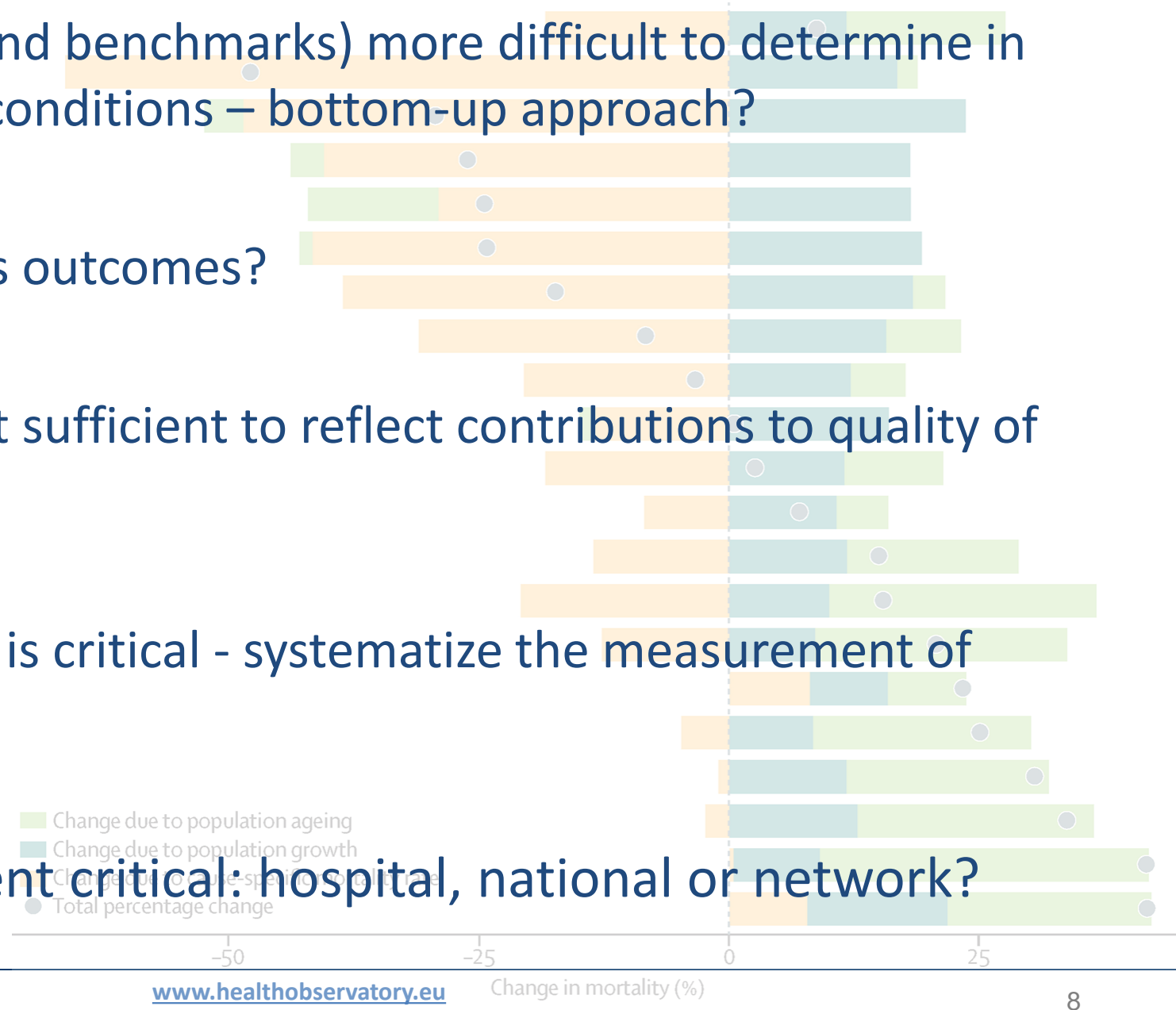
- Need to pair activities with adequate funding
- Costing model for ERN activities necessary – also for voluntary staff time
- Cost-volume model to improve proportionality of funding among participating centers?
- Diversification of funding?





Making the business case: outcomes?

- Outcome variables (and benchmarks) more difficult to determine in short term for some conditions – bottom-up approach?
- Educational targets as outcomes?
- Process indicators not sufficient to reflect contributions to quality of care
- Patient-centeredness is critical - systematize the measurement of patient satisfaction?
- Level of measurement critical: hospital, national or network?





Outlook for the long-term vision of ERNs

Does this reflect your experience?

