

ERN integration into national systems:
challenges and opportunities

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Conflict of interest disclosure:

I have no actual or potential conflict of interest in relation to this presentation.



European
Reference
Networks

24 networks of excellence in RD

➤ Kick-off: 2017-03-09

24 networks, >950 competence centers, **>700 000 patients/year**

**Showing excellence in
clinical practice, research and education
Pioneers in the field!**

Disruptive innovation:

New organizational cultures;

Displaces older systems and ways of doing things.

...benefits far beyond virtual care

- **Sharing** of scarce resources for clinical practice and research;
- Ensure “**home for every RD**”;
- **Care pathways**: national and cross-border;
- **Patient** empowered and empowering (incl. PROMs and PREMs);
- **Data** (incl. for policy-making/ health statistics - surveys, registries, real-world data);
- **Quality assurance**: independent assessments, continuous monitoring;
- **Supranational collaboration**:
 - *Best practices: clinical guidelines, care pathways;*
 - *Patient registries, epidemiological surveillance;*
 - *Teaching and training;*
 - *Research: basic – translational – clinical trials;*
 - *Solving unsolved: undiagnosed diseases.*

**Aim: improve health outcomes, enhance patient care experience, reduce costs
AT A NATIONAL LEVEL**

“Nonetheless important objective is the ability for networks to become integrated in the national health care systems.

In other words, **what is the use of enormous amounts of expertise if they remain confined to the individual centres participating in the network?**



These centres must be able to reach all patients in their territories – and in other Member States, if no national reference centre has been established – in order to really make a difference to the care of these patients. Thus, ERNs are effective only in so far as they are inclusive, proactively reaching out to the populations they serve.”

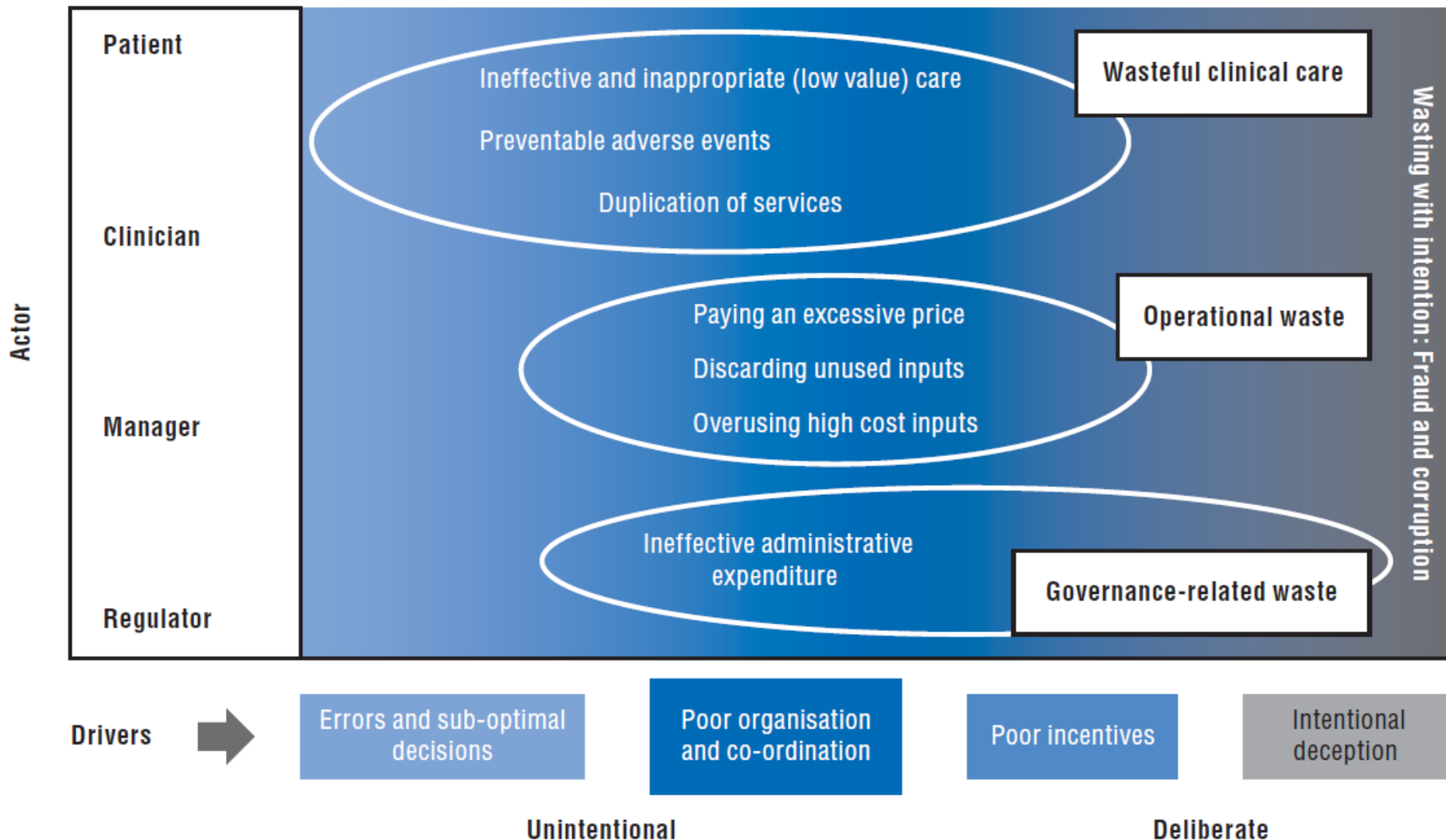
– *Expert Panel on Effective Ways on Investing in Health (EXPH):
Opinion on Application of the ERN model in European cross-border
healthcare cooperation outside the rare diseases area, 26 Sep 2018.*



Navigation of patients, data and funds

No knowledge on wasteful spending in RD care

Figure 1.1. **Three categories of waste mapped to actors involved and drivers**





BoMS/ ERN CG Working Group on ERN integration into national systems

- Situation analysis: **survey** (18 MS);
- Draft **Position Paper**;
- **Areas** for intervention:

National policies/ legal framework;

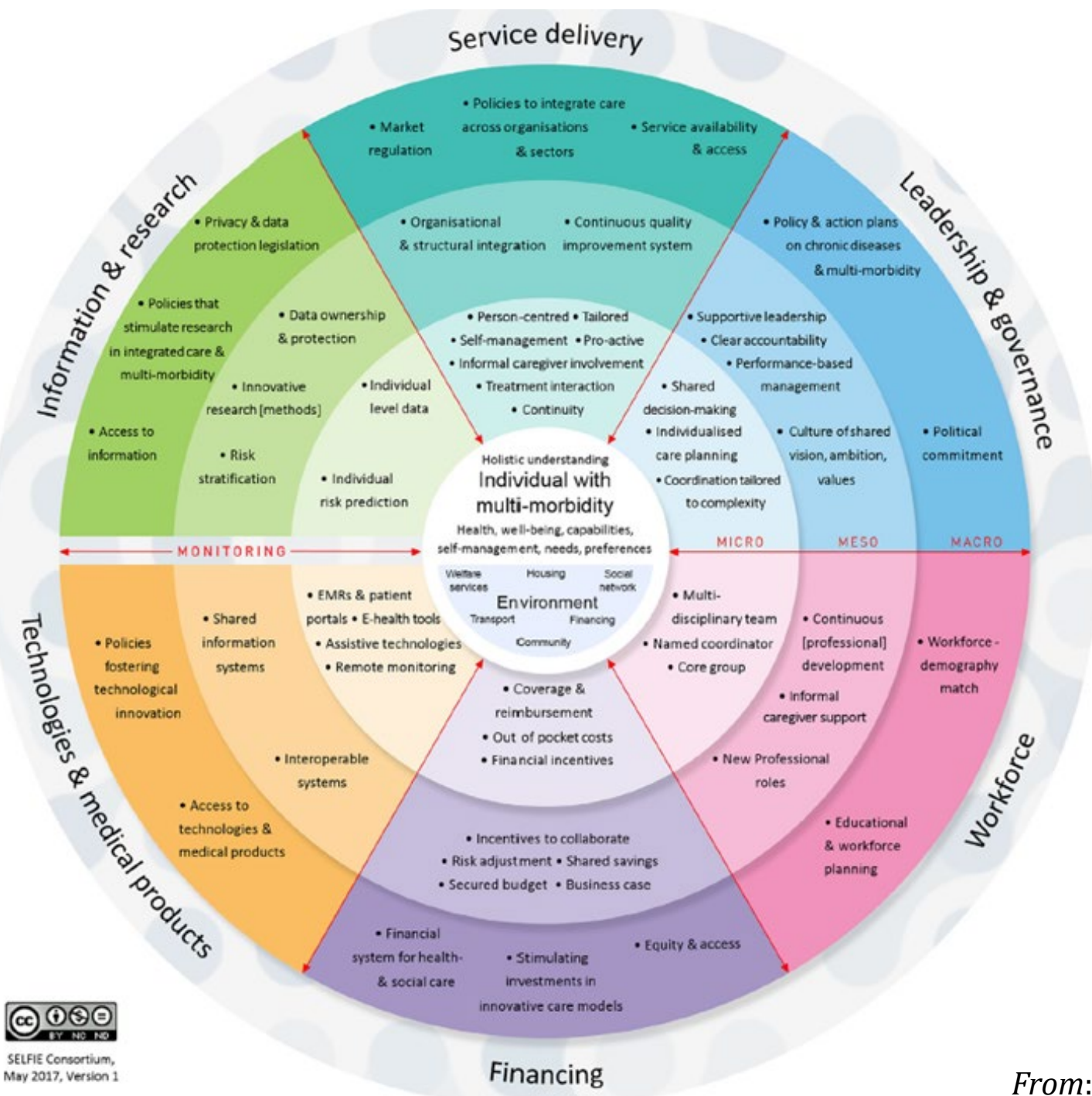
Patient pathways/ referral systems;

Support by MS to ERNs and CoE;

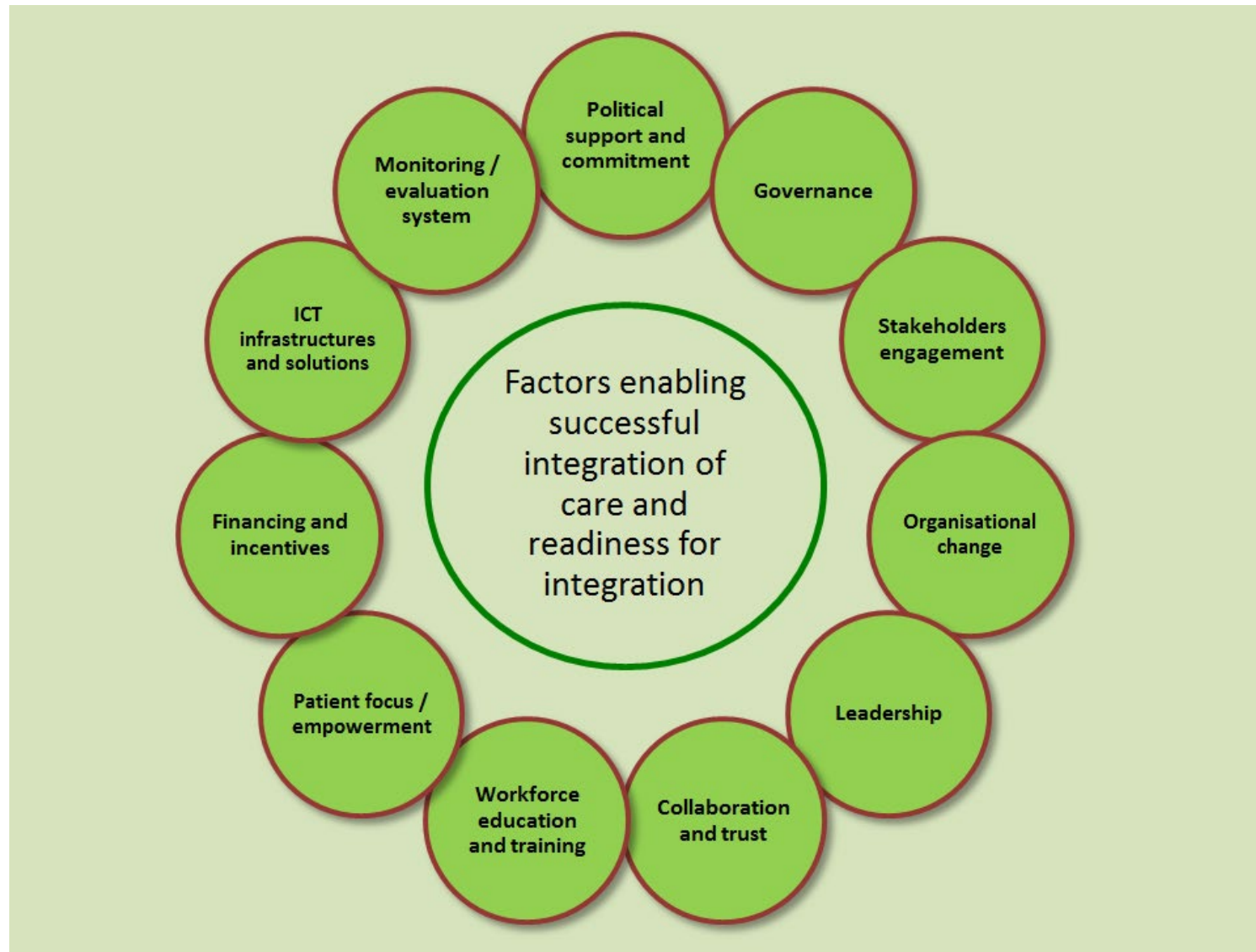
Information on ERNs, awareness raising.

- **Prioritization:** patient pathways/ referral systems;
- Collection of **best practices:** policies/ legal regulation, organizational, informational, ICT measures.

Some lessons:
 integrated care;
 care provision for
 chronic diseases/
 multimorbidity/
 cancer



Identified factors that enable successful integration of care



*From: **BLOCKS. Tools and methodologies to assess integrated care in Europe.**
Report by the Expert Group on Health Systems Performance Assessment © European Union, 2017*

Rare diseases are remarkably unique



➤ **Rarity, numerosity, heterogeneity**

– limited ability to recognize/ provide care at a primary medical contact point;

Care pathways (vertical integration with removal of any delays), workforce education, referral systems.

➤ **Heterogeneity, multisystem nature**

– heterogeneity of pathways, multiple contacts with healthcare system;

Care pathways (complex networks and not a “one way route”, tertiary-tertiary care interface, reducing barriers in regionalized HC systems.

➤ **Complexity: diagnostics, treatment, long-term care**

– limited expertise and resources, expensive infrastructures;

Need for centralization of infrastructures and human resources.

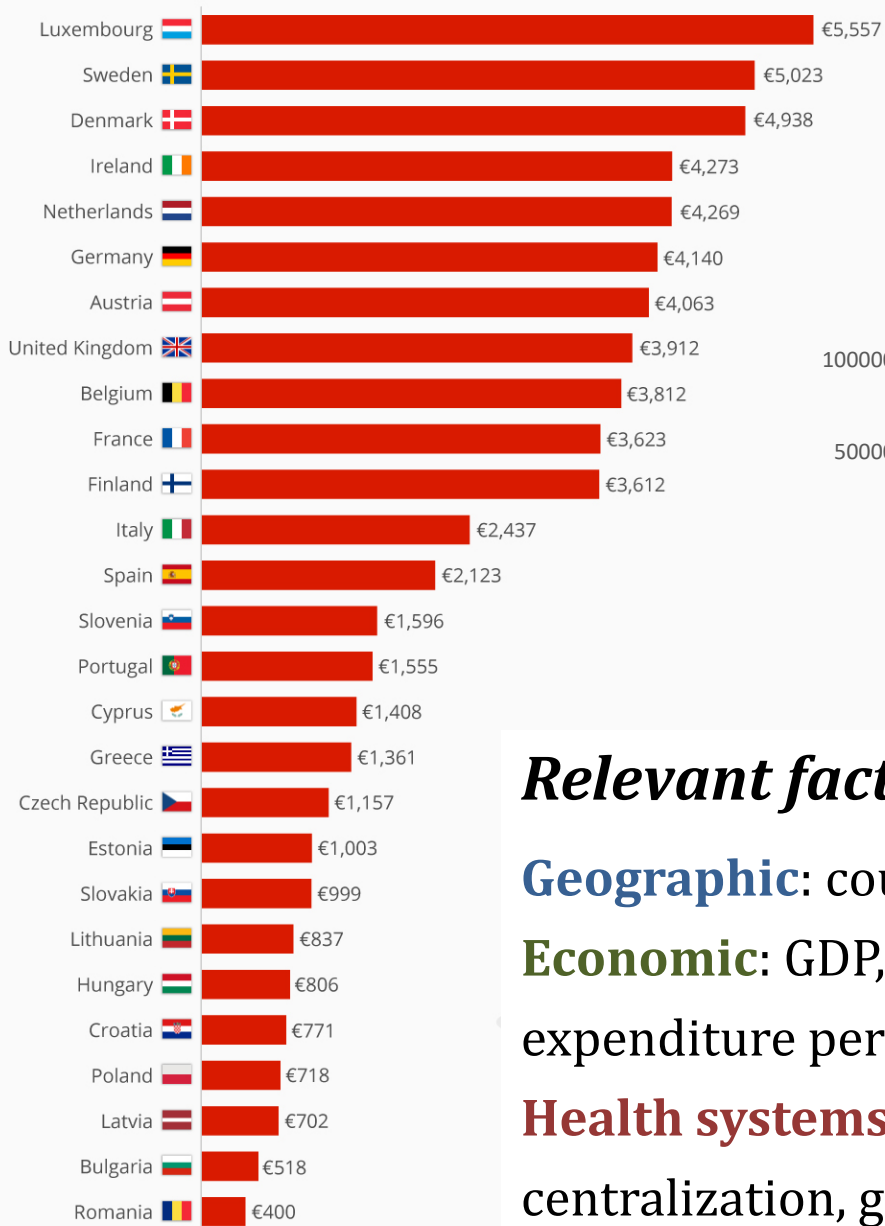
➤ **Chronicity, disabilities**

– multiple movements across healthcare system, intersectoral collaboration;

Longitudinal, holistic approach, transition, patient empowerment, balanced provision of centralized/ decentralized services.

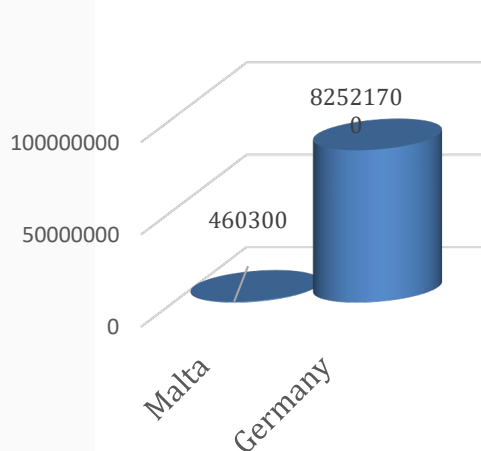
EU Healthcare Expenditure Relative To Population Size

Healthcare expenditure per inhabitant in 2015*

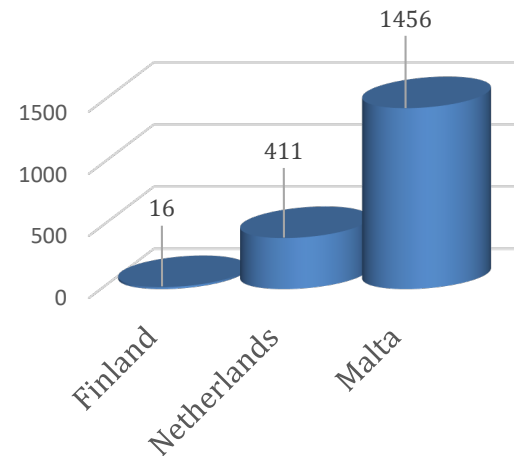


Our diversity: geographic, economic, health system

Population



Population density



Relevant factors:

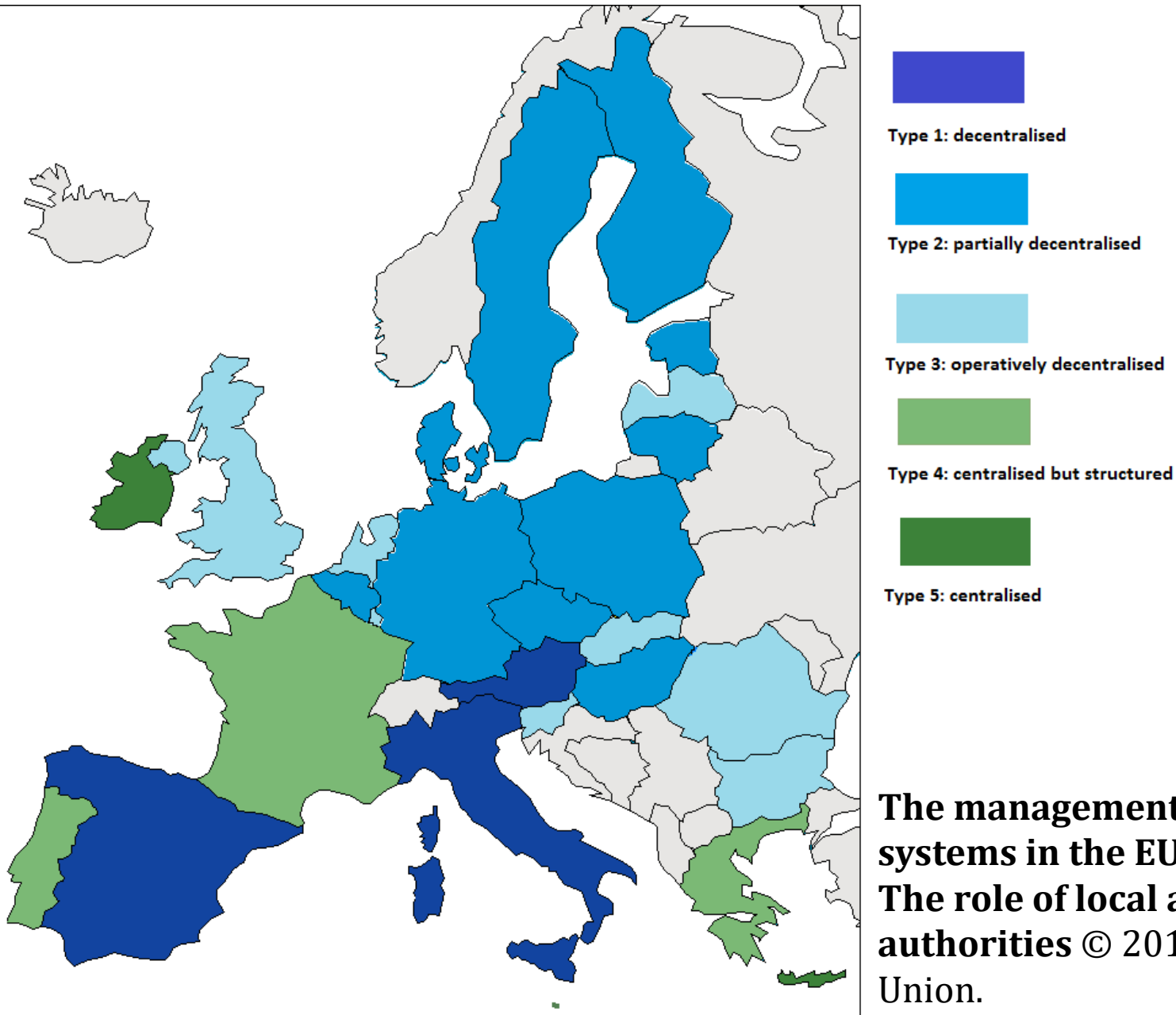
Geographic: country/population size, population density

Economic: GDP, healthcare expenditure per capita

Health systems: HC system type/centralization, gatekeeping/referral system, level of expertise

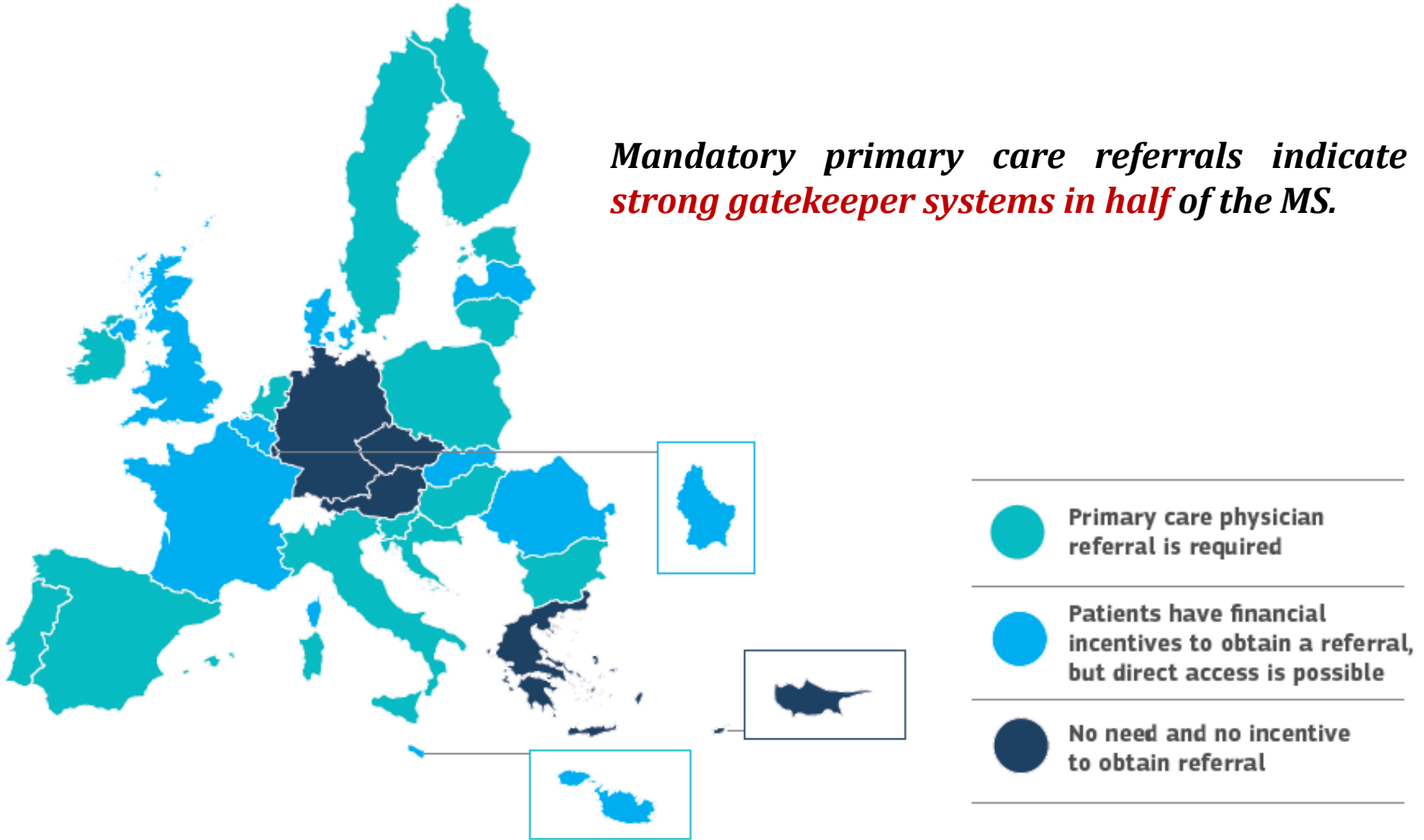


Our diversity: different types of health management systems



The management of health systems in the EU Member States - The role of local and regional authorities © 2012, European Union.

Our diversity: gatekeeper systems in healthcare



Some best practice examples

legal/organizational/informational/digital measures

- **FR: political support and commitment**

the 3rd French National Plan for RD, 23 networks - *filières de santé* - encompassing 387 reference centres and 1800 competence centres.

- **IT: stakeholder engagement in the regionalized HC system**

interregional cooperation for rare cancers and other RD.

- **FI: care pathways in a country with low population density**

Congenital heart defects: centralized diagnostics and surgery, regional follow up, pathways enabled by centralized specialty training in pediatric cardiology.

- **IE: leadership and national coordination**

National Rare Diseases Office (NRDO) as a coordination hub and an information point (Orphanet Ireland) for all ERN-related activities and stakeholders.

- **LT: organisational change for reducing administrative delays in RD care pathways**

reduced gatekeeping function of GP in chronic complex diseases with direct access to long-term care management by named tertiary-level physician.

...and many more



CoE in ERNs: equal partners in the game

Diverse, autonomous national systems



Conclusions:

- There is no “one size fits all” solution: consideration of national geographic/economic/health system factors and unique RD features.
- Need for best practice collection/ exchange and mutual learning among MS.

General framework of “to do list”:

- Political support and commitment.
- Legal, organizational, financial and ICT arrangements of care pathways and referral systems.
- Education, information, awareness raising.

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Thanks for your attention!