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# ERNS' MAIN CHALLENGES FOR THE FUTURE

**ERNS in Action: 4<sup>th</sup> Conference  
on European Reference Networks**

Brussels, 22 November 2018

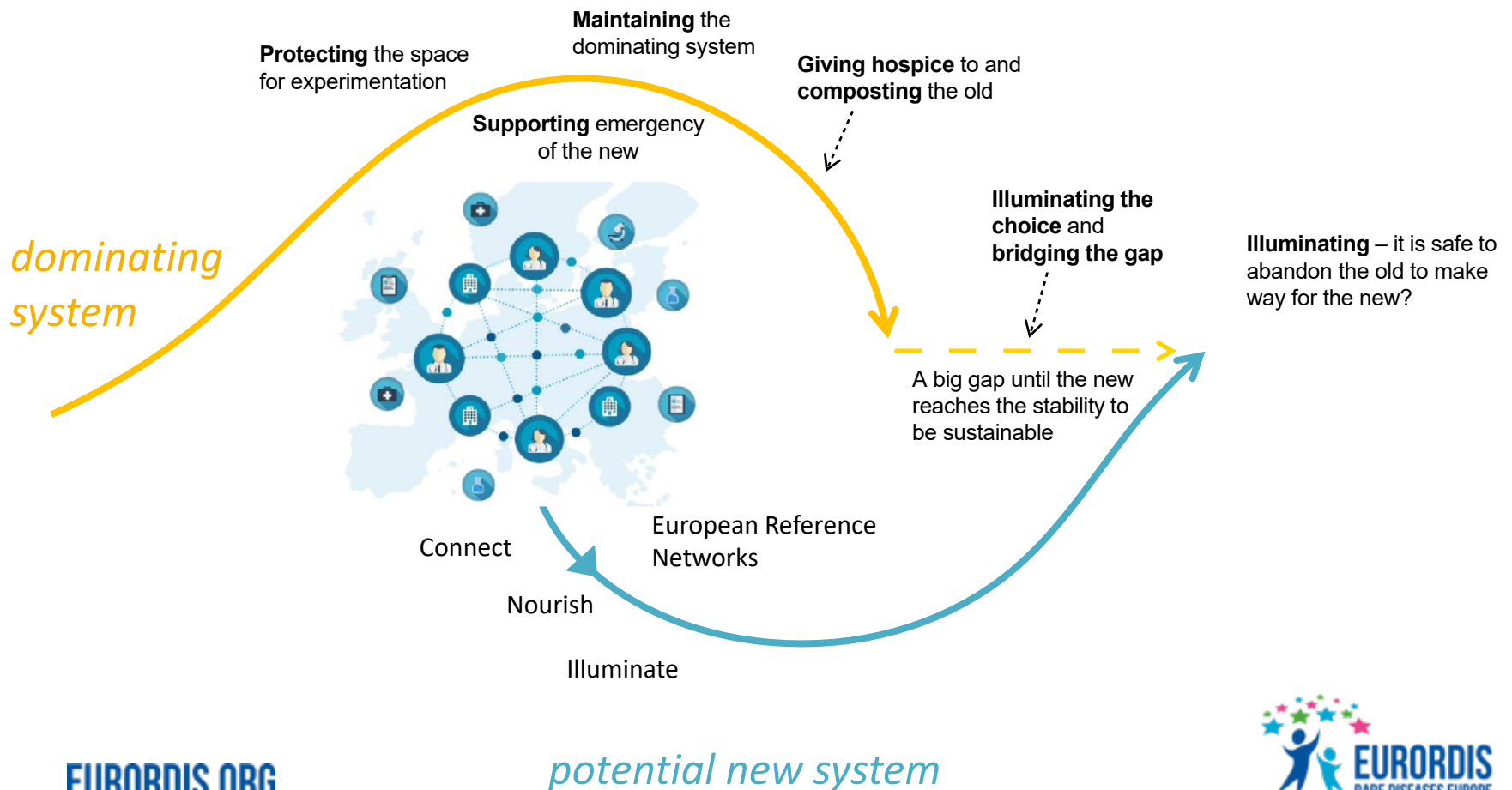
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# ERN: Our Paradigm Shift

Berkana Institute  
Two-Loop model

*A system is inclined to self preservation.*



# Immediate Challenges

Goal: Consolidate Networks and coordinate their expansion to ensure balance representation of experts & proportional coverage of Member States

## Sustainability:

- Limited resources for the networks & limited good will.

## Business continuity:

- Safeguard against loss of key and valued leaders and expertise (U.K. Brexit).
- Limited and diminishing capacity due to heavy administrative burden.
- Only a few Members are really active and are taking responsibility.

## Enlargement of Networks:

- Keeping Networks manageable!
- Ability to manage Next Call for New Members of Existing Networks – Open vs. Restricted.
- Adoption of a common model for Network Member between Member States
- Alignment of Member States endorsement of expertise under national law

# Short-Term Challenges

Goal: Networks delivering their full ambition, moving to full service provision (set out in EU legislation) and meet the multi-system needs of Rare Diseases.

## Sustainability:

- Ring-fence capacity and commitment of HCP Members to be active in the ERNs.
- Securing sustainable funding: MMF negotiations and National Structural Funds prioritization
- Sustainable Network Business Model that diversifies funding - grants, voluntary contributions and public-private partnership.
- Build (and fund) essential networks infrastructure in particular registry platform.

## Business continuity:

- Lack of independent multi-stakeholder advisory body to provide strategic direction.
- Integration of ERNs into NHS through referral pathways and contractual relationships.
- Public confidence in Network expertise, quality control, safe-guarding patient safety.

## Enlargement of Networks:

- Multi-professional Membership and inter-ERN collaborate
- Defining rights and obligations of Full and Affiliated Members

# Medium-Long Term Challenges

Ultimately, to fulfil public expectations and address the EU public health needs of Rare Disease

## Sustainability:

- Long-term EU policy commitment, action and funding is needed to fully realize ERN potential.
- Sustainable business model = sustainable workforce and accumulation expertise and knowledge.
- Formalisation of legal entity of Networks = contractual relationships with MS & Stakeholders.

## Business continuity:

- Shared vision and ERN Roadmap to manage expansion of networks (e.g.: services, infrastructure & data)
- Clear commissioning intentions and investment from Member States
- Establish public-private partnerships and provide assurance of networks autonomy

## Enlargement of Networks

- Expanding the networks scope and provide equality coverage of all rare diseases.
- Address the imbalance between networks scope, size and resources.

# Priority Areas



## Five Critical Priority Areas:

1. **Keeping Networks manageable**, reduce administrative burden and prevent Networks capsizing due to overwhelming number of Members.
2. **Define rights, expectations and obligations** for Members and Hospitals & MS to ring-fence capacity and commitment of Members to be active in the ERNs.
3. Planning now to develop a **sustainable Business Model that diversifies funding** - grants, voluntary contributions and public-private partnership.
4. **Investment in ERN infrastructure** is essential for Networks to deliver their legal mandate.
5. Creation of an **independent multi-stakeholder expert group** to provide strategic direction and oversee implementation.



# Thank YOU ERN Coordinators, Clinician & Patient Members, Member States & Commission

