

Position of the Hospital managers

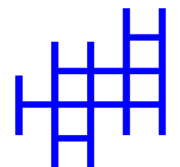
Dr. César Velasco Muñoz

“I have no actual or potential conflict of interest in relation to this program/presentation”.

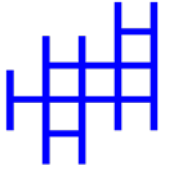
Parallel session PS5: "ERNs Sustainability"



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A shared vision of ERNs present and future

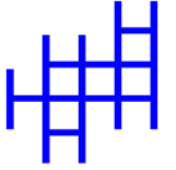


3 pillars for ERN sustainability

- Sharing data & knowledge
- Better care & outcomes
- Patients & Society



Sharing Data and Knowledge



Challenges

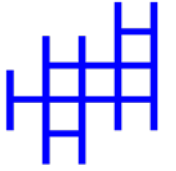
- Different **classifications** (ICD10, Orphanet...)
- Admin tasks, workforce, **Burn-out**
- Triple **registration** (EU, National, regional...)
- Different **languages**
- Different ERNs in a not connected intra-center.

Possibilities/opportunities

- Standardized classification for the EU (**Universal coding**)
- Automated extraction clinical data, allocated resources.
- Harmonized registries and **interoperability**.
- Natural language processing → artificial intelligence
- Join efforts and knowledge by creating a **shared virtual structure**, patient agendas, information systems within the hospital.
- **Local ERN interdisciplinary members network.**

“ERN brings an exciting new way of working together with EU colleagues, but for some professionals it means, more work with the same resources”

Better care & outcomes



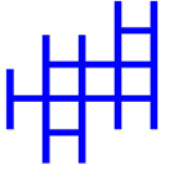
Challenges

- Heterogeneous care pathways...**variability**
- **No outcomes** measured: Clinical, PROMs & PREMs
- Non patient centred care and organizational culture
- Knowledge about what to do but ... how to do it? How to embed it in the daily activity?
- **How to improve** the current care
- ERNs **focused on the clinical condition, Hospital KPIs (efficiency vs. Quality).**

Possibilities/opportunities

- ERN **Clinical Guidelines** and Process
- Measure outcomes in terms of health and experience.
- Organizational innovation. **One time, one place, multiple specialists.** Pediatric to adult transition.
- Design and measure processes, patient pathways and organizational structure.
- **ERN beyond healthcare:** Research, training and innovation.
- Creation of a **Hospital ERN Managers Network**, involving hospitals and public administration for commitment.

Patients & Society



Challenges

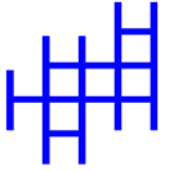
- **Induced demand** – why is it happening
- Despite highly specialized attention, primary care plays a role (not only in the follow-up)
- **Inequality** in access
- High costs for **diagnosis and treatment** (Orphan drugs)

Possibilities/opportunities

- **Communication guidelines, training** professionals and society.
- **Involving Primary Care and Social Care.** Dissemination and promotion beyond the hospital.
- **Patients associations** advocacy and stakeholders commitment. Co-design: managers and PAGs collaboration for prioritizing hospital actions.
- The role of the Pharmaceutical Industry: **shared financing, pay per value, risk sharing**... Public procurement of innovation.

“We must ensure a minimum standard of care in EU hospitals, an imbalance in available resources between different hospitals needs to be avoided”

European University Hospital Alliance



- As a hospital network are **committed** with the sustainability of ERNs.
- Committed with **care and value**.
- **Research, training & innovation**

