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Analyzing Health System Resilience From the Perspective of Rare Diseases

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Background

Health systems resilience (HSR) is generally understood as the capacity to absorb, adapt or transform in order to maintain essential functions when facing shocks. As a notable example of such shocks, the COVID-19 pandemic disrupted many activities in different sectors of the health system.
Vulnerable groups, such as patients with **rare diseases,** have been heavily impacted by discontinuation of traditional healthcare activities caused by the pandemic because of their unique demands and the requirement for ongoing care.

To be prepared for future shocks and to avoid issues experienced during the recent pandemic research in the field is essential to fill the present gap about the lack of understanding of **factors affecting HSR** and practical strategies to achieve it.

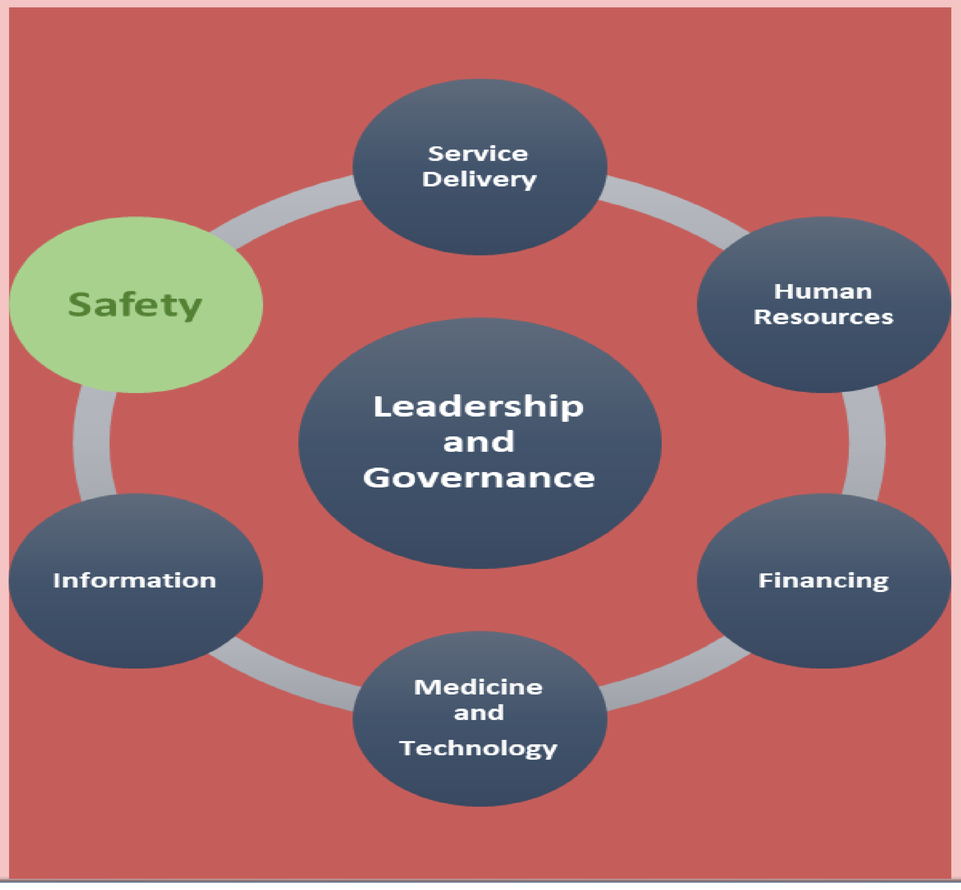
Objective

The present study **aims at exploring HSR in the field of rare diseases by:**

- **Finding the characteristics of HSR through a scoping literature review and providing a classification of features related to HSR using well-recognized framework**
- **Identifying the determinants of HSR in the context of rare diseases**

Methods

- A **scoping literature review** was performed to identify relevant studies dealing with HSR
- **Identification of characteristics** related to HSR from studies identified
- Classification of the characteristics using **WHO building blocks** (6 main blocks) plus one additional building block, i.e. **safety**
- Based on characteristics identified within each block, development of a **survey** directed to healthcare professionals dealing with *rare diseases* to understand to which extent each characteristic matters for achieving HSR in that context. After the development of a preliminary draft of the survey, comprehensiveness and clarity were assessed, sharing the survey with a *restricted group* of experts working and not with rare diseases. Based on their feedback, the survey was revised and shared among the target group.



Results

We identified **53 characteristics** relevant to HSR and classified them in 7 different building blocks as shown in Figure.

Leadership & Governance	Financing	Service Delivery	Medical Product & Technology	Information	Health Workforce	Safety
• Surveillance system • Emergency policies • Decentralization • System indicators • System capacity • Equity • Multisector collaboration • Logistic • Trust • Transparency • Guidelines and Protocols • Community involvement • Global solidarity	• Effective use of resources • Diverse financial resources and mobilization of fund • Protection of resources • Minimizing the risk of being under funded	• Maintain high quality of services • Prioritization • Stability of services • Pathway	• Providing essential demands • Strategic inventory reserves • Forecast on shortage • Alternative suppliers	• Anticipation* errors and issues(• Data base decision making • Collection and analysis • Policy making • Analysis of capacity • Continuous improvement • Effective communication infrastructure • Reliability • Accessibility • Absence of complication • Diverse source of information • Data quality management • Protection	• Train and up to date • Multi skills • Psychological support • Encouragement • Compensate • Financial support • Adequacy • Commitment	• Equip system by infectious prevention equipment • Equip system by immunization technology • Risk management • Safety notification and guidelines • Train staff for safety reasons and increase awareness

Feedback from the restricted groups used to test clarity and comprehensiveness of the survey was generally positive, and minimal changes were introduced to improve the clarity of the survey and to include specific questions in addition to characteristics found in the literature review (i.e., the importance of being part of a large network dealing with a rare disease).
The survey was implemented online using EUSurvey (https://ec.europa.eu/eusurvey/) and then shared using social media and direct mailing the link to experts in the treatment of rare diseases.

Collection of data is still ongoing. At present a total of 22 answers were collected coming from 6 countries. Preliminary data collected shows that **health workforce and leadership & governance** building blocks have more impact on HSR, while there is *no consensus* about **medical products and financing**.

Conclusions

The data collection through the survey is ongoing and we are organizing *webinars* to gather professionals in the field of rare diseases to motivate more experts in our network within Europe to participate in the research. In the long term, we expect our **framework** to suggest strategies to effectively deal with shocks in the context of rare disease treatment to improve prepardness of health systems .

References

- World Health Organization (2007). Everybody's business – strengthening health systems to improve health outcomes: WHO's framework for action. WHO; Geneva.
- Emami, S., Lorenzoni, V., Pirri, S., & Turchetti, G. (n.d.). The characteristics of health care resilience: Scoping Review. (under preparation)
- Link to the survey: https://ec.europa.eu/eusurvey/runner/hsr

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