

Health Systems Resilience for Rare Diseases: preliminary results of a narrative review.

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Work Package 2

OBJECTIVE

In the framework of the "Joint Action RD-ACTION", a literature review of the available publications on health systems resilience was defined in order to identify and understand mechanisms that influence health systems resilience for rare diseases (RDs), taking into account principles of equity, quality and efficiency.

METHOD

Narrative review of the literature to select publications on health systems resilience for RDs. Health descriptors: health systems, healthcare organization, sustainability, equity, resilience, governance, prevention, citizen/patient/families empowerment, rare diseases. Databases: PubMed, EBSCOHost, EMBAL, PASCAL, EMBASE, STN International and GoogleScholar (gray literature). Language of publication: English, French, Spanish and Italian. Years: from 2000.

RESULTS

- 97 papers were identified and analysed according to criteria of quality of interventions, efficiency and equity.
- The review took into account the Communication from the European Commission on effective, accessible and resilient health systems: capitalising on experience and work carried out over recent years, and with a view to further developing approaches at EU level, the Communication from the European Commission focuses on actions to strengthen the effectiveness of health systems, increase the accessibility of healthcare and improve the resilience of health systems.
- In relation to the resilience, and building on experience of recent reforms, the Commission has identified the resilience factors that helped some health systems safeguard accessible and effective healthcare services for their population (see figure 1).
- The narrative review carried out in the RD-Action identified two main topics:
 - Economic evaluation
 - Networks



Figure 1. Communication from the European Commission on effective, accessible and resilient health systems. COM(2014) 215 final. Brussels, 2014.

Economic evaluation

1

The available evidence on the adequacy of economic evaluation for decision-making, based upon allocative efficiency for incorporating or excluding technologies for rare diseases shows that there is no widely accepted criterion in the literature to weigh the expected utilities, in the sense of assigning more weight to individuals with greater health needs. Other methodologies are needed to complement cost-effectiveness studies, weighting utilities asymmetrically (that is, everyone is treated equally).

Networks

2

The knowledge of people's relationships and the analysis of social networks in the field of public health is becoming increasingly important. Several countries, such as United Kingdom, Netherlands, Italy, United States and Australia include patients associations in health systems studies, including their sustainability.

CONCLUSION

The reviewed papers underline the importance of strengthening the scientific basis of decision-making by means of epidemiological, economic and applied research to health systems and services, so that health needs can be satisfied on a population and equity basis, while safeguarding allocative efficiency. These mechanisms represent at the same time the key for health systems resilience for RDs, while patients' associations stand for a powerful voice of interest defence.