

# EQUITY AND HEALTH SYSTEM SUSTAINABILITY FOR RARE DISEASES.

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## Work Package 2

- Pursuing health protection is the ideal inspiring health systems. Nowadays, sustainability of health systems is being challenged by social and demographic pressures, technological advances and increasing costs. The financial crisis and austerity policies with cuts of public health-care budgets jeopardized health equity. Sustainability and equity of health systems for Rare Diseases is facing nowadays these problems.
- The World Economic Forum has identified inequality as a major risk to human progress. Extreme economic inequality and political capture are too often interdependent. Left unchecked, political institutions become undermined and governments overwhelmingly serve the interests of economic elites to the detriment of ordinary people. According to the International organization Oxfam, several countries have successfully reduced economic inequality by means of cracking down on financial secrecy and tax dodging; redistributive transfers; and strengthening of social protection schemes; investment in universal access to healthcare and education; progressive taxation; strengthening wage floors and worker rights. Oxfam calls on governments to use their tax revenue to provide universal healthcare, education and social protection for citizens. Moreover, it has recommended policies in multiple contexts to strengthen the political representation of citizens to achieve greater equity, underlining the importance of citizens' active participation in the mechanisms of resilience.
- In the framework of the Joint Action for Rare Diseases (Joint RD-Action) "Promoting Implementation of Recommendations on Policy, Information and Data for Rare Diseases", a narrative literature review was carried out in order to identify and understand mechanisms that influence the sustainability, equity and resilience of health systems for rare diseases.
- The narrative review identified networks as important sustainability and resilience mechanisms. In particular, it valued European Reference Networks (ERN), that are networks connecting health care providers and centres of expertise of highly specialised healthcare, for the purpose of improving access to diagnosis, treatment and the provision of high-quality healthcare for patients with conditions requiring a particular concentration of resources or expertise no matter where they are in Europe. The cross-border and cross-sector collaboration represents a ground-breaking development in the field of healthcare cooperation and is widely seen as the beginning of a new era for European action in health services.
- The sustainability of health systems for Rare Diseases can not be separated from the analysis of the context and the action on it, including fiscal equity. Networks play a relevant role for health systems sustainability, since they are based upon, pay special attention to and can intervene on health systems knowledge development, partnership, organizational structure, resources, leadership and governance.
- Resilience is an inner mechanism of communities and organizations to counterface hardship. However, it is not meant to substitute governments' responsibility to promote and protect citizens' health.