

Work Package 2



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COMMUNICATION FROM THE COMMISSION On effective, accessible and resilient health systems

The Communication from the European Commission on effective, accessible and resilient health systems focuses on actions to strengthen the effectiveness of health systems, increase the accessibility of healthcare and improve the resilience of health systems.

'A health workforce of adequate capacity and with the right skills' is one of the resilience factors that helped some health systems safeguard accessible and effective healthcare services for their population, as well as identified by the Commission. It is essential for finding innovative solutions through organisational and technological change.



Merging narrative medicine and digital technologies could be an innovative solution towards fair, equal and sustainable health systems, particularly for rare diseases.

Narrative Medicine

Narrative medicine can be useful in several areas, as indicated in the ISS *Recommendations on Use of Narrative Medicine in clinical care for Rare and Chronic Diseases*: prevention, diagnosis, therapy and rehabilitation; adherence; team work; self awareness of health professionals; burn-out prevention of professionals and caregivers; promotion and implementation of diagnostic-therapeutic-assistance paths; optimization of economic resources; prevention of legal disputes and defensive medicine.

The sense of powerlessness and isolation among patients, families and professionals are common in rare diseases – due to clinical and social implications – and narratives and stories are often the main tool to support the health pathway.

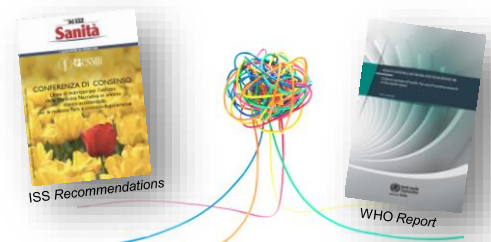
Moreover, WHO highlights that the use of narrative research alongside more traditional methodologies will enable organizations to shift from a narrowly biomedical and epidemiological approach to a more values-based approach that is better able to incorporate (and respond appropriately to) diverse cultural contexts.

New technologies

At the same time, new technologies open new possibilities and new relational models.

In the past, technological innovations offered health professionals sophisticated and more and more accurate tools.

The impact of the current **digital health revolution** is different: today the patient has prompt access to technological tools, information sources and relational support. Simultaneously, online conversations about illness and treatments allow the patient to share fears and expectations.



Care relationship seems to becoming more complex. An innovative solution...

Digital health can create an experience of disease and therapies outside the strictly medical context, with risks but also new opportunities.

RISKS like as a progressive disintermediation of medicine as a reference for knowledge and methods for health management. **OPPORTUNITIES** like as the development of new epidemiological, diagnostic and therapeutic paradigms that integrate narratives and technologies, in a biopsychosocial perspective. Technology enables nurturing the simultaneous use of structured quantitative data, laboratory tests, and non structured qualitative (narrative) data.

An **INNOVATIVE SOLUTION** for facing the risks is the development and use of digital platforms, for the application of narrative-based medicine in clinical practice, according to the ISS *Recommendations*. They could more easily allow the share and personalization of the diagnostic-therapeutic plan, intertwining narratives of patients, caregiver and clinical teams.

They could be flexible solutions, also for European Reference Networks, for fair, equal and sustainable health systems, especially for rare diseases.