Working group 24:

eHealth: improving rights fulfilment through innovation

Background

Telemedicine refers to healthcare services delivered remotely via telecommunications. They include teleconsultations, telemonitoring, telediagnosis, prescriptions provided remotely via telephone, or mobile health apps. These systems usually encourage self-care, e.g. self-measurement of blood pressure or blood sugar levels, thus reducing the need for hospitalisation and costs. Health-related apps are a fast growing sector in the healthcare system. However, the way organisations manage the data collected still remains unclear and it is often not clearly explained how health apps collect, disclose and use personal data.

Telecare is the provision of healthcare services aimed at transferring parts of the care process from hospitals to the patient's home, enabling patients to remain independent. It allows a coordinated system between health and social care. There is evidence of the benefits of telecare for older people, people with disabilities and their carers.

eHealth solutions also include all those services facilitating access to health information – for instance, access to online medical records by patients.

In 2012, the European Commission published the 'eHealth Action Plan 2012-2020 – Innovative healthcare for the 21st century'. It encourages EU Member States to apply Information and Communication Technologies to their healthcare systems.

Objectives

This workshop looked into different forms of eHealth, such as telemedicine, telecare and mobile health. It explored how technological developments have improved patients' experience of healthcare and, ultimately, the right to health. As eHealth services usually involve processing sensitive information, such as the patient's health data, the workshop also examined the privacy and data protection challenges associated with new eHealth technologies.

Speakers

- Heidrun Mollenkopf, Vice President, AGE platform Europe
- Laurène Souchet, Secretary General, European Patient Forum
- Francisco Sanchez Laguna, Head, Information Systems Coordination Department, Andalusian Health Service

- Claudia Prettner, Policy Officer, Unit for Health and Well-Being, Directorate General Communications Networks, Content and Technology, European Commission
- Ludovica Banfi, Programme Manager, FRA
- Elise Lassus, Research and Administrative Assistant, FRA

Main messages

1. Access to electronic health records should be legally regulated, and restricted to medical and healthcare purposes.
2. Fundamental rights should be clearly spelled out and embedded in all eHealth initiatives ('fundamental rights by design'), notably: 1) ensuring equal access to eHealth for all groups, and 2) safeguarding the respect of privacy and data protection principles.
3. Patient empowerment should be fostered through greater involvement at all stages (design, implementation and monitoring), including by providing transparent and easily understandable information about available eHealth solutions.

Promising practices

- The Blue button initiative supports the portability of eHealth records, US.
- SAFER guidelines address the safety of patients in eHealth, US.
- Topping up the funding provided by the public health system to increase patients' choice of eHealth devices, Germany.
- Medical doctors are involved in setting up the e-Health record system, Andalusia, Spain.
- Cost-free helplines for patients, operated by healthcare professionals, available 24/7 (including translation), Andalusia, Spain.
- Patients have the possibility to select which personal data (including health data) can be shared, Estonia.
- eHealth records for individuals who only have access to emergency healthcare (i.e. migrants in irregular situations), Andalusia, Spain.

Next steps

- All Member States should ensure effective patient access to their own records through Electronic Health Records platforms.
- National health authorities should perform systematic evaluations of eHealth strategies/solutions to improve patients' health and access to healthcare, with specific attention to groups at risk of exclusion.
- Local and national authorities, NGOs, patient organisations and professional groups should raise awareness and foster understanding to enable patients to give informed consent regarding the use of their personal data.
- The European Commission should embed fundamental rights compliance in all EU funding for eHealth.

- National health authorities should provide alternatives for individuals who do not want to make use of e-tools to access their healthcare.