PATIENT’S PERSPECTIVE ON EHEALTH

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A STRONG PATIENTS’ VOICE TO DRIVE BETTER HEALTH IN EUROPE
Who is EPF?

- European Patients’ Forum
  - Umbrella organisation
  - Active since 2003
  - Independent & non-governmental
  - EU patients’ voice

- Our members
  - 67 patients’ groups
  - Disease-specific EU & national coalitions

- Our vision
  - All patients in the EU have **equitable access to high-quality, patient-centred** health and social care
EPF eHealth projects

Joint Actions: Interoperability, Cross-border eHealth

Telemedicine

Electronic Health Records

Users perspective on Telehealth

Integrated care

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E-Health: patient expectations versus realities
Patients’ expectation in eHealth

Facilitates chronic disease management
And leads to improved quality of life

Involvement in the care process as equal partners with HCPs

Information, Health literacy

Patient centred care as opposed to disease centred

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Common mistakes in eHealth services development and deployment

- Neglecting the human dimension
- Failing to assess/evaluate added value, quality and safety of care
- Neglecting digital health literacy challenges
- Forgetting health inequalities & diversity
- Failing to involve users
Can eHealth contribute to deliver on patients’ rights?
Access to healthcare

• eHealth can contribute to fulfill the right to access healthcare: e.g. can improve accessibility, help tackle healthcare workforce shortage issues, help overcome geographical barriers, facilitate cross border healthcare

• But it can also create new divides: access to internet, low health literacy

• Inclusion of underserved or potentially vulnerable groups in the development process is essential

• Affordability and reimbursement model is also a key question for ehealth and mhealth
Our definition of empowerment

“Patient empowerment is a process that helps patients gain control over their lives, increasing their capacity to act on issues that they themselves define as important”

(Adapted from JA-PaSQ, 2012)
Does eHealth require patient empowerment or does eHealth lead to patient empowerment?
Patient involvement in eHealth why does it matter

A right

The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.

Alma Ata Declaration – Principle IV (1978, WHO)

“All EU health systems aim to be patient centred”

Council Conclusions on Common values and principles in European Union Health Systems 2006

Beneficial

• Ensuring services are tailored to the needs of end users
• Ensuring it fits in their lives
• Taking into account community setting
• Trust and acceptability essential for take up of eHealth services
What meaningful involvement in eHealth looks like

Patient = Expert

Involve patients throughout the design cycle

Not just a patient satisfaction survey

Appropriately resourced, planned and evaluated

Meaningful patient involvement

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A concrete case: Patient Access to EHR

- Ownership
- Masking Data
- Management bad news
- Content accessibility
- Patients’ input into EHR

"This is where the idea for the new EHR starts getting a little complicated."
Conclusion

- eHealth is seen as a key solution towards patient empowerment, improving quality of life, more self management, and sustainability of healthcare
- To achieve of this eHealth need to be developed in a patient-centered way
- Developers and decision makers need to actively include health equity and patient empowerment into their strategies
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