eHealth and patient empowerment: A patient perspective

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EPF involvement in eHealth

- We are a **non-governmental umbrella organisation** set up in 2003

- We represent

  - ✓ 61 pan-European and national patient organisations active in the field of European public health and health advocacy

  - ✓ 150 million patients with chronic conditions across the EU

- **VISION**: All patients with chronic and/or lifelong conditions in the EU have access to high quality, patient-centred equitable health and social care.

- **MISSION**: to ensure that the patients' community drives policies and programmes that affect patients' lives to bring changes empowering them to be equal citizens in the EU.

Equitable
Independent Inclusive
Empowering Patients Holistic Transparent
Patient-Centred Non-discriminatory Consultative

EPF involvement in eHealth

Challenges faced by chronic patients

- **Chronic conditions affect 80% of people** over **65** and often involve multiple morbidity.

- **Healthcare systems are still geared toward acute care**, despite the rising prevalence of chronic diseases.

- **Multi-morbidities** are unrecognised and untreated, or not optimally treated

- **Burden of living with one or more diseases** not only for healthcare system but for the individual and their families.

- **Lack of integrated care -** within healthcare and between health and social care

- Patients with chronic diseases often report that they do not receive adequate support from the healthcare system, and are left with the impression that they have to **"fight the system"** to get the services they need.

Need for a sustainable shift in healthcare

EPF European Patients Forum

- Policies aiming only at short-term cost savings are likely to lead to a higher cost in the long run – both to the health system and to society.

- From a patients' perspective, the path towards sustainability should be based on quality of care and equity of access.

- **Costs of limited health literacy**: 3–5% of the total healthcare costs at system level

- The shift needed in healthcare: **patient centeredness** (starting from **real needs** and not from **technology**)

- Win-win: Patient-centred care models have been shown to be **cost-effective** as well as improve **patient satisfaction** and **clinical outcomes**

- **eHealth as mainstream care and integrated health and social care**

eHealth as part of the solution

Patient-centred eHealth can be part of the solution if it:

- helps HCPs maintain a closer eye on the health status of the patient and facilitates **chronic disease management**

- **does not undermine** (possibly improve) **patient healthcare-professionals relationship and** does not **replace direct patient-health** professionals contacts

- is designed around the **needs of the patient** and not the **disease (especially telemedicine services)**.

- helps improve **adherence** to treatment and life-styles and enable **concordance**

- facilitates and is accompanied by **patient empowerment**

Exploring Empowerment

EPF European Patients Forum

Do patients want to be more empowered?

- ❖ **92%** of **patients** are willing to play a more active role in managing their own condition

- ❖ 60% of patients would be **willing to use eHealth** in the short-medium future

- ❖ …but only **48%** thinks they are ready to handle the additional responsibilities presented by eHealth

Chain of **TRUST**
Understanding patients' and health professionals' perspective on **Telehealth** and building confidence and acceptance

Exploring Empowerment

How about health professionals?

❖ **70%** health professionals would be **willing to use e-health** in the short-medium future

❖ …but only **20%** said that management promotes the use of e-health

❖ …and only **29%** believe that their patients will be in the position to use e-health service safely

Defining empowerment

Patients' having the ability to:

a) **understand health information**

b) make an effective use of it to inform **sound health decisions** in the context of everyday life,

c) and **participate** in a meaningful way in health-related decision-making in an **equal partnership with health professionals.**

(SUSTAINS definition of patient empowerment)

sustains

SUSTAINS Patient Empowerment Model

EPF — European Patients Forum

Patient knowledge	Patient control	Patient participation
Link between patient and his/her understanding and use of health information	Relationship between the patient and the management of his/her condition	Relationship between patient and health professionals

Support from health professionals

Meaningful Patient involvement in health

Patients' empowering potential of eHealth services

EPF European Patients Forum

Patient empowering potential of eHealth services (eHealth ERA project):

Category 1: eHealth information tools and services for citizens/patients focusing on the electronic provision of health and wellness information to citizens.

Category 2: eHealth management support tools and services for citizens/patients focusing on applications which allow citizens to interface with health service providers electronically in order to better support their use of health services. Patient accessible EHR, ePrescriptions (etc).

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Category 3: eHealth homecare and telemedicine tools and services for chronically ill citizens (patients) focusing on applications that allow citizens who are receiving healthcare to be supported in their personal environment, whether fixed or mobile, outside traditional healthcare facilities, e.g. telemedicine.

RENEWING HeALTH REgioNs of Europe WorkiNg toGether for HEALTH

PALANTE PAtients Leading and mANaging their heaLThcare through EHealth

smartcare

eHealth and patient empowerment

Does eHealth require patient empowerment or does eHealth lead to patient empowerment?

Patient empowerment

eHealth

eHealth and patient empowerment
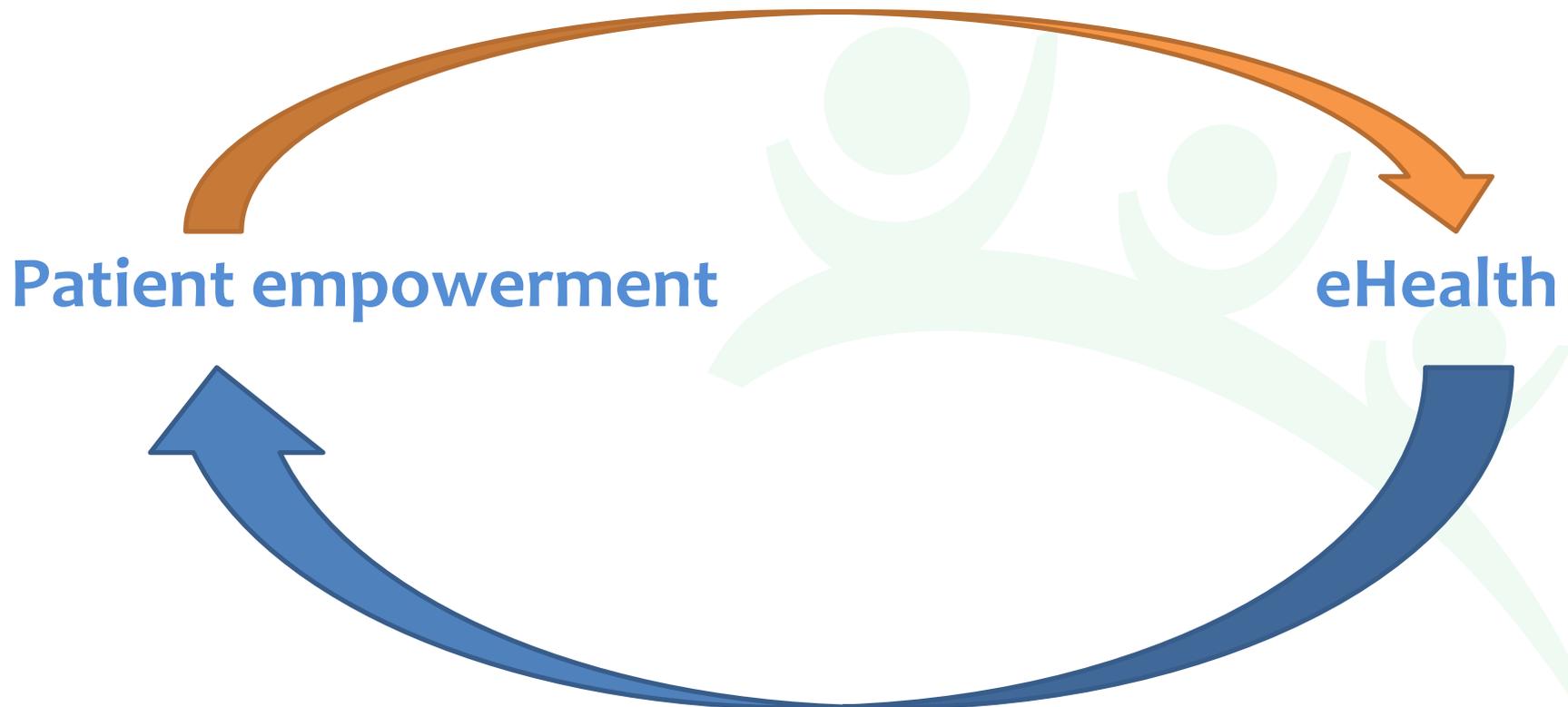
Patient Empowerment:

- A **process** and an **outcome**

- A **pre-condition for large scale eHealth implementation**

- An enabler of patient-centred healthcare – patient from "**passive**" receiver to **active user** of health services

- A key "shaper" of the **changing relationship between patient and health professional(s)** – "**co-production**" "**therapeutic alliance**" "**concordance**"

- Leads to **better health outcomes** - optimal outcomes of health care interventions are achieved when patients become active participants in the healthcare process

The case of patients' access to EHR

Changing patient-HCP relationship

- Patients are more prepared during visits

- Quality of consultations/interaction is higher as patients are more **knowledgeable** about their health

- Patients prepare questions in advance

- Patients are able to draw HCPs attention to issues important to them

- Patients are able to participate in decision-making (**concordance**)

- **Adherence** is improved as a result of **ownership**

eHealth and patient empowerment

- Patients, when informed, empowered and involved, are an asset to society

- Patients are willing to take on a more important role in their treatment, but they do not receive adequate support.

- An effective empowerment strategy needs to encompass:

  ➢ **High quality, accessible information**: need for an overarching EU strategy

  ➢ **Health literacy:** capacity to obtain, interpret and understand health information; to make sound health decisions; and to navigate the health services

  ➢ **An enabling healthcare environment,** implementing the principles of patient centred healthcare

eHealth and patient empowerment

- All eHealth services entail **some degree of responsibility shift** from health professionals to patients

- Giving patients more responsibility for their own care does not necessarily mean we are ultimately "empowering" them

- For empowerment to happen we need **commitment and actions of health professionals,** i.e. education and support

- Patient empowerment requires **developing new skills among health professionals,** e.g. new interaction arising from the use of eHealth

- Obviously empowerment can occur at different levels and patients have different ideas about what it means to them and what it takes to become empowered.

eHealth and patient empowerment

- **Important caveats:**

- **Respect** patients' willingness to get involved – or not

- Do not over-estimate patients' **capacity** to get involved

- Patients in vulnerable situation – no shifting of burden of "responsibility" on them

- Patients <u>already</u> observe much – healthcare staff need to <u>listen</u> more, take their views seriously

- Decisions as to whether offer eHealth to a patient need to be based on a thorough assessment of the specific **physical, psychological situation of the patient**, taking also into full account the social environment in which the patient lives.

- **Appropriate support** and **enabling environment** is key