



From technological innovations to deployment & user acceptance

MovingLife Project: Scenario workshop on future mHealth
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European Patient Forum (EPF)

Umbrella body of **51** European level disease-specific patients' organisations *and* national coalitions of patient organisations

Focus: chronic diseases - there are some 150 million patients with chronic conditions in the EU

Vision: high quality, patient-centred equitable healthcare across the EU

Areas of work:

- eHealth and Telehealth
- Patient Safety & Quality of Care
- Information to Patients - Health Literacy
- Patients' Mobility – Cross-border healthcare
- Health Research
- Health Technology Assessment
- Pharmaceutical Package



Rationale behind EPF's involvement in & commitment to eHealth

- eHealth services and solutions can only work if patients are involved **meaningfully** from inception to delivery to ensure that they are in line with the needs and expectations of those who will actually use them
- Patients tend to be the **weakest stakeholders** in eHealth: the involvement of organisations representing them in eHealth policy-making at all levels is therefore crucial
- Exciting **new developments** in eHealth & healthcare innovation and EPF has chosen to be there to ensure that patients are properly engaged in shaping the future

eHealth as a Priority

EPF and its members identified eHealth as a core policy & programme priority due to its huge potential in:

- Improving **patient safety** by eliminating errors commonly associated with paper-based medical records
- Enhancing the **continuity of care** in the home environment through telehealth and telecare
- Helping **reduce health inequalities** and **improving accessibility** for patients living in rural and remote poorly served areas
- Allowing for a more **patient-centred** disease management
- Enhancing the **relationship** between **patients** and **healthcare professionals**, through **better more efficient communication**
- Strengthening **personalised healthcare** for patients
- **Empowering patients** and enabling them to be more involved in managing their health

Challenges & barriers to overcome if we are to unfold all this potential:

- More **solid data** to produce **sound evidence of real benefits** (esp in telemedicine, thousand of small pilots but poor evidence of benefits & comparability of results)
- Bringing about more **legal clarity** & addressing **ethical issues** at EU and national level (liability, reimbursement, confidentiality, etc.)
- Overcoming **organisational issues** and “**resistance to change**”
- Resolving **technical issues** (technology is not a problem in itself but interoperability is) – **eHealth in need of mHealth**
- Developing **strategies** at European, national and regional level
- Overcoming **market fragmentation**
- Strengthening **user acceptance** (mainly, but not exclusively patients and health professionals)

Focus on patient acceptance

Patient acceptance is too often **disregarded** or **not considered as one of the main driving forces** behind eHealth development while it currently represents one of the key barriers

We need to investigate **what is behind user acceptance:**

- Enhancing the **understanding of factors determining patient acceptance**
- Research demonstrated that **patient involvement is key while in eHealth it has been so far very limited:**
 - too late when processes and services have been already developed
 - attempt to “convince” patients rather than engage with them to understand their attitudes, requirements & constraints and design services which fulfil their expectations to the largest extent possible.

Focus on patient acceptance

- **Going beyond user requirements** to integrate patients expectations & patient outcomes (other than clinically-relevant outcomes)
- **Efficiency in the way eHealth is communicated** to patients – patients are not effectively reached out
- **Patient empowerment** is considered crucial to eHealth, but we do not invest enough in creating the conditions to make this happen (poor focus on patient literacy and eHealth, self-confidence, etc.)
- Users are regarded as separated groups while we need to **strengthen trust and mutual understanding** as the implications of eHealth on patient-professionals relationship are potentially very high
- **Perceptions of patients who have used eHealth are far more positive** than patients who have never used it, meaning that many perceived barriers can be overcome through targeted training & investment in health literacy



Projects: from practice to policy to practice

EPF and the wider patient community are committed to supporting the deployment and wider uptake of eHealth by providing solid evidence of benefits.

For this very reason we identified the following priority areas:

- Exploring patient acceptance
- Integrating user requirements, needs and expectations right from the onset
- Patient - professionals relationship with a focus on confidence and trust
- Health literacy
- Establishing networks at EU-level with other key stakeholders to put patient at the centre



Projects: from practice to policy to practice

How do we do this?

1. Projects

- **Chain of Trust** on telehealth users' confidence and trust
- **Renewing Health** on real life telemedicine pilots
- **SUSTAINS** on patient access to electronic health records

2. Joint actions

- **eHealth Governance Initiative** co-leading the task force on Trust and Acceptability in eHealth

3. Cooperating with other stakeholders

- **eHealth User Stakeholder Group**
- **High level Task Force on eHealth**
- **Transparent dialogue with eHealth industry players**



Led by EPF on patients' and health professionals' confidence and trust in telehealth services (Public Health Programme, 2011-2012)

- **The paramount objective** is to advance the empowerment of patients and health professionals across Europe in their understanding and effective use of telehealth services
- **Two specific objectives:**
 1. **Improve available knowledge of views, needs, barriers and expectations** of the main end users of telehealth services across the EU to see:
 - whether & how views have evolved since the initial deployment of telehealth
 - what barriers there still are to building confidence in and acceptance among users
 2. **Raise awareness and understanding of user perspective** on telehealth

Expected outcomes

- Through a Literature review, EU-wide survey, 6 national workshops & 4 European focus groups:
 - unique & unprecedented **assessment of the views, needs, benefits & barriers** related to telehealth from the perspective of patients & health professionals.
- Through 6 National roundtables, a documentary, and final conference
 - **increase the knowledge & understanding of the specific perspective** of health professionals & patients amongst various stakeholders.

Findings & recommendations will constitute a unique **tool to inform policies and decision-making**

First public deliverable including project preliminary outcomes

- **Quarter I 2012**

Project Final Report and Documentary

- **Quarter III-IV 2012**

Final conference

- **Brussels December 2012**

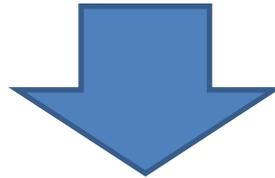
Demonstrate that telehealth based services **optimise the use of resources in health provision**, improve **patients' quality of life, healthcare professionals' satisfaction** while **enabling patient involvement and empowerment**



- **19 trial sites in 9 European Regions on Diabetes, COPD, CVD** grouped in **9 clusters**
- Common Multidisciplinary Assessment Methodology (**MAST**)
- Involving Telehealth Users through the **User Advisory Board**

Many Renewing Health services are delivered through mobile applications

Mission of **RENEWING HeALTH User Advisory Board**



to operate as a **standing advisory committee** for the Consortium to advise and provide on-going feed-back on the needs of users of the piloted telehealth services



the UAB should ultimately improve the fit between the services and requirements, expectations and constraints of the various end user groups

Focus: Patients' access to Electronic Health records (should be possible from mobile devices as well)

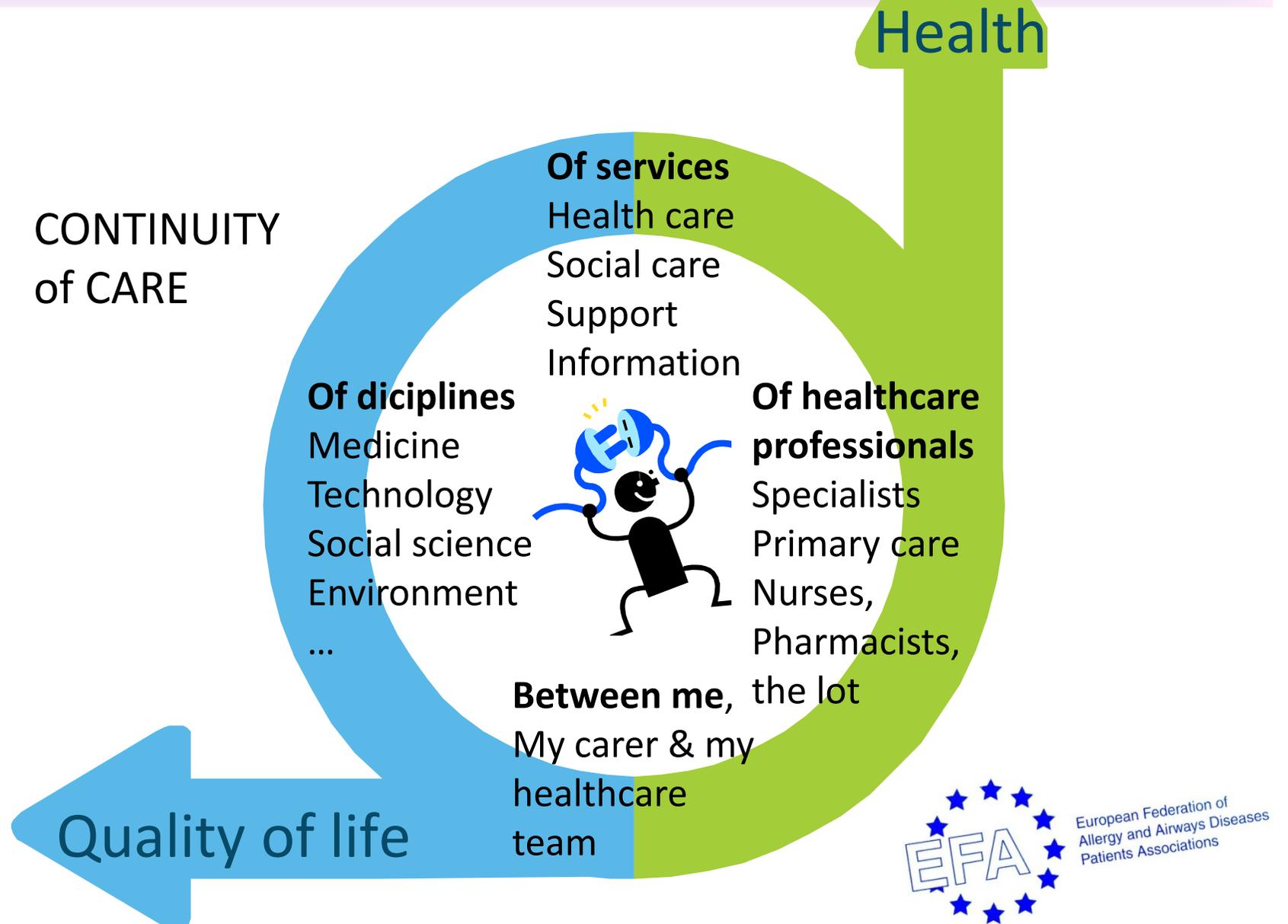
Objective: Developing and deploying patient-centered services in 11 regions giving patients access to Electronic Health Records in order to:

- **Strengthen patient empowerment** (EPF in charge of this component)
- **Enhancing Continuity of care** (Progress in treatment especially of chronic diseases need efficient and continuous contact between the patient and the professionals in order to achieve optimal medical result)
- **Efficiency and economy,** (with the new treatments available, and the growing demand from patients/public, there is a need for improved efficiency and economy).

The way forward

- **Patient and health professional acceptance** needs to be repositioned at the top of eHealth priorities
- **Patient empowerment** is key to eHealth, but we need to **create the conditions**: an EU-wide strategy on health literacy & information to patients & carers, including “eHealth literacy” is needed to build the necessary skills and knowledge to enable patients to use innovative eHealth solutions with confidence
- **Technologies developing from needs** - not the way around: in the past the innovations have often been technology-driven rather than users' needs-driven
- **Patient involvement needs to take place right from the onset** in both eHealth policy-making and service design
- Need to start looking at **synergies between health and social services** through the use of ICT and with patient needs at the centre
- Need to **capitalize on existing good practice** and investigate into what has to be done in order to replicate this good practice in different contexts

Connectivity! Patient at the Centre?



Finally...

New technologies? YES

New patients? YES

New networks? YES

YOU ARE the LEADERS.

THE PATIENTS ARE YOUR

ENTHUSIASTIC CRITICAL PARTNERS



THANK YOU

www.eu-patient.eu

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