Digital transformation of the health workforce – reflections from a patient perspective

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SEPEN Workshop - Digital health: what are the implications for supply, demand, monitoring and organisation of health workforce?
25 June 2020

@eupatientsforum

“A STRONG PATIENTS’ VOICE TO DRIVE BETTER HEALTH IN EUROPE”

EPF European Patients Forum

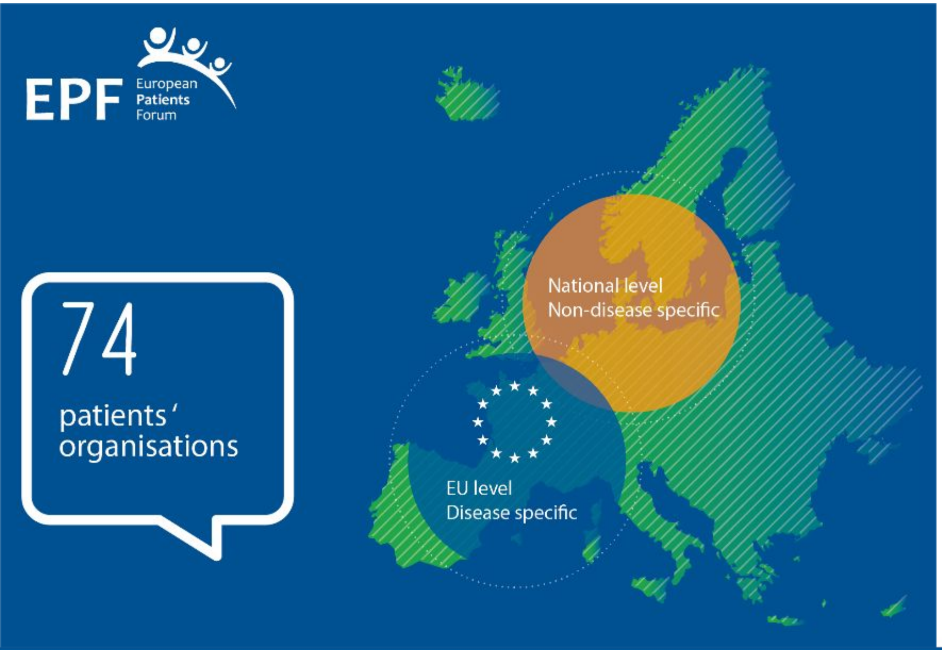
About EPF – European Patients’ Forum

Who we are

- Set up in 2003, based in Brussels
- Independent NGO
- Pan-European, cross-disease umbrella patient organisation

Our Vision

“All patients with chronic conditions in Europe have **equal** access to **high quality**, **patient-centred** health and related care.”



Our Mission

“to be the **collective, influential patient voice** in European health and related policies and a driving force to advance patient empowerment and patient access in Europe.”

“ A STRONG PATIENTS’ VOICE TO DRIVE BETTER HEALTH IN EUROPE ”

EPF’s work on digital health - policy

Position Statement	on the **General Data Protection Regulation** –*2012*
Position Statement	on **Informed consent** in **clinical trials** –*2016*
Guide for patient organisations	**EU Regulation on the protection of personal data:** what does it mean for patients? –*2016*
Position Paper	on **eHealth** - *2016*
Reply	Public consultation on Transformation of Health and Care in the Digital Single Market –*2017*
Working Group	**Digital Health –** set up to support our work in this area and provide expertise –*2018*
Briefing on data	Enabling patient communities to provide meaningful input to policy discussions – *2019*
Patient survey	on **Electronic health records** and data sharing – 2019-2020
Consultation Response	On European Commission’s **Data Strategy and White Paper on AI**

EPF’s work on digital health – projects and initiatives

EPF
European
Patients
Forum

calliope
Call for Interoperability

RENEWING HeALTH
REgioNs of Europe WorkINg toGether for HEALTH

Digital
Health
Europe

sustains

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

smartcare

EHDEN
EUROPEAN HEALTH DATA & EVIDENCE NETWORK

Data
Saves
Lives

EU Communication on digital health (2018)

I. Secure access to and sharing of data

- Access to health data is a citizen's right
- Cross-border patient summaries, ePrescriptions, proposal on full EHR

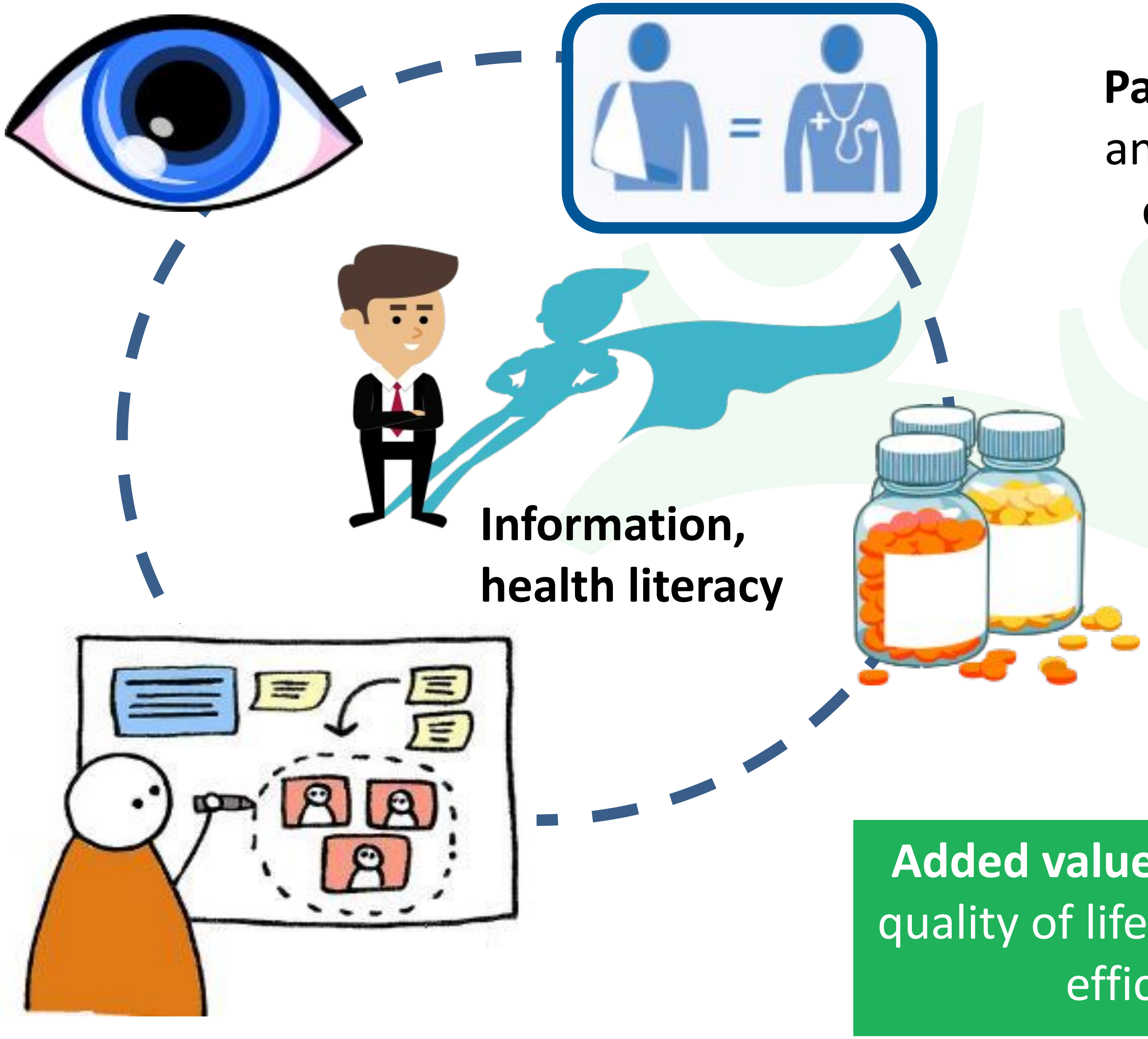
II. Citizen-centred healthcare solutions and services

- Common principles and certification; support uptake healthcare providers, mobilise public funding
- Emphasis on integration and coordination of services along the "continuum of care"

III. Pooling of data for effective and efficient research

- Voluntary collaboration mechanisms, e.g. "one million genomes by 2022". specifications for secure access and exchange of health data; pilot actions, e.g. rare diseases

Patients' expectations of digitalisation



Facilitates
chronic disease
management,
self-management

And leads to improved
quality of life

Patient empowerment and involvement in the care process as equal partners with HCPs

Information, health literacy

R&D to develop more effective treatments

Person-centred as opposed to disease-centred care, **better coordination**

Added value: better outcomes – clinical, quality of life – patient safety – effective & efficient health systems

Patients and HCPs' views on digital health

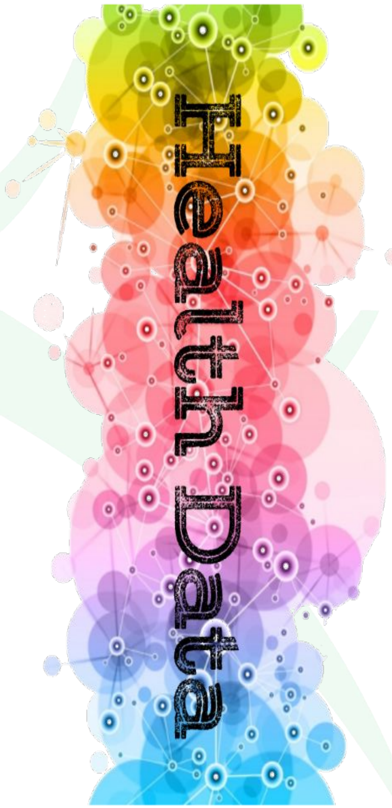
Chain of TRUST
Understanding patients' and health professionals' perspective on Telehealth and building confidence and acceptance

- 92% of patients are willing to play a more active role in managing their own condition
- 60% of patients (and 70% of HCP) would be willing to use eHealth in the short-medium future
- … but only 48% think they are ready to handle the additional responsibilities presented by eHealth. **Similar trends can be recorded for HCPs**
- **Digital health**, in particular EHR, is understood as a potential key tool to **enhance communication with HCPs**

Data use / re-use for health research

Patients are generally comfortable and willing to share health-data – vital importance to advance health research, help other patients, and ultimately benefit society

- Find solutions to unmet needs (e.g. rare diseases)
- Improve quality of care, treatment, and quality of life
- Patients learn from their own data – empowerment
- Help others – general community and peer support
- Have already experienced the benefit of research themselves
- Trusted environment – healthcare and research setting



EHR survey – key messages

1/3 said they have access to their EHRs

1/2 do not and **1/5** did not know

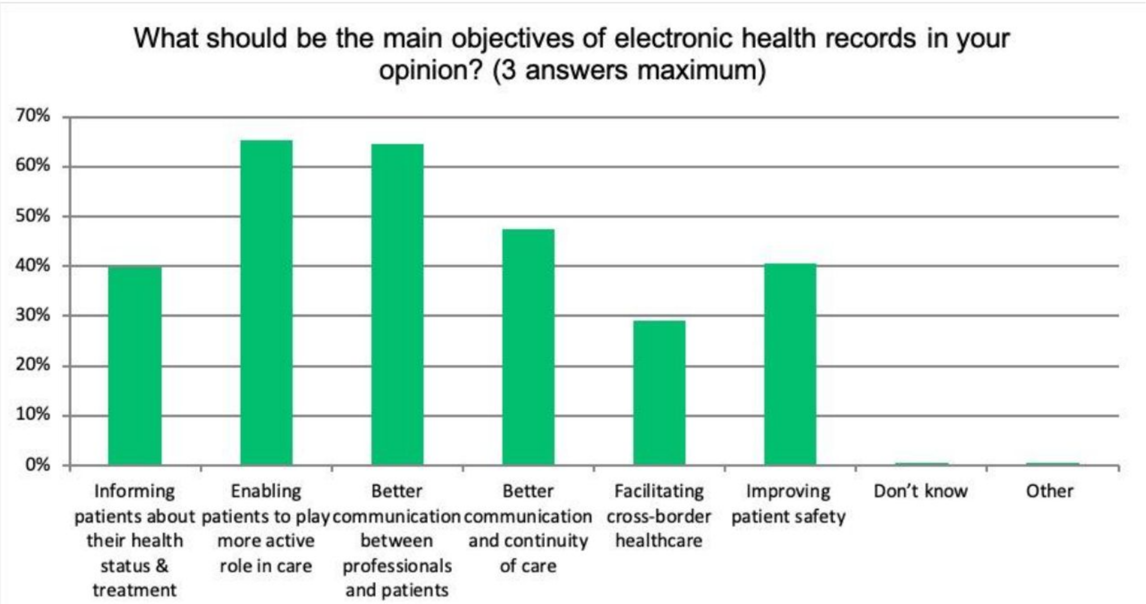
Most have view-only access

86% want access to their EHRs

74% want full access

19% would agree to a summary

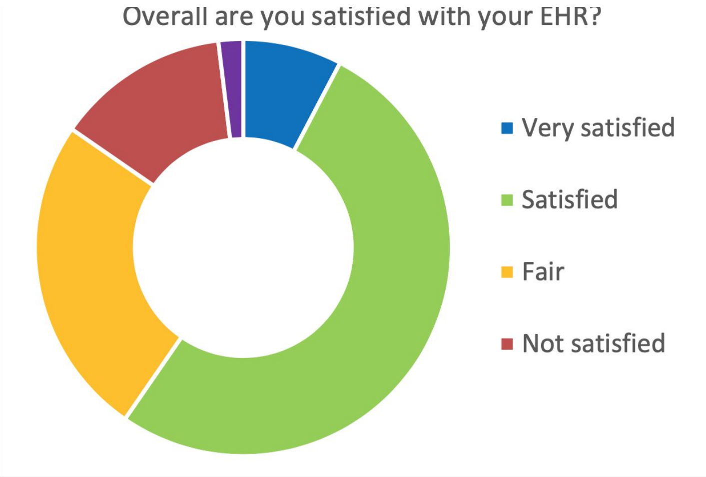
1/3 said their EHR information was **not accurate or up to date**


What should be the main objectives of electronic health records in your opinion? (3 answers maximum)

Patients want **support to understand** the information in their EHRs – but also **HCPs to get better at presenting and communicating information**

Patients would like to be able to

- update their information
- report wrong information
- add new information such as family/personal history
- provide details of symptoms and side effects


Overall are you satisfied with your EHR?

Using data together to improve quality of care

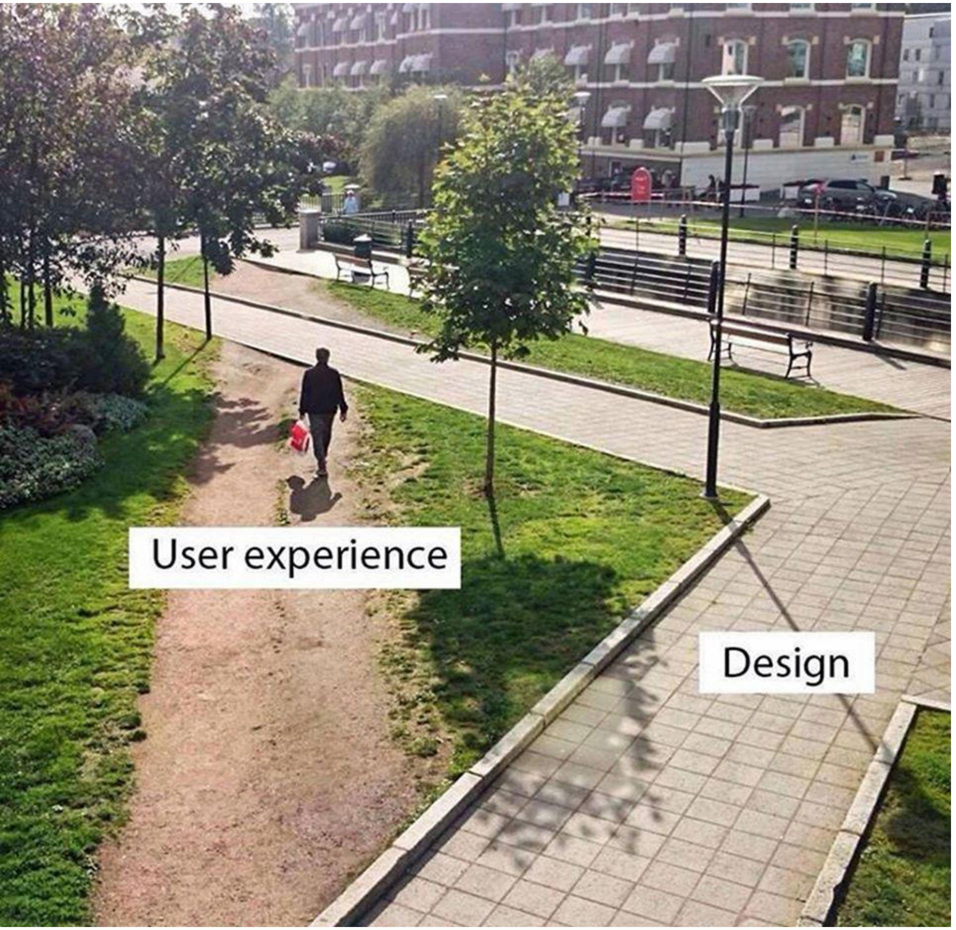
- To make informed decisions, patients & HCPs need data (–> evidence)
  - More realistic picture of “what works” or what could work
  - Addressing unwarranted variation in care
- Shared decision making (SDM) is about dialogue: communication skills are fundamental
- SDM still far from embedded in healthcare – patients’ choices not always respected
  - Cultural change needed
  - Patients and HCPs should work in partnership to better understand and discuss data and implications of new

Let’s not forget process in the quest for outcomes

- Relational / human aspects of care highly valued by patients – more complex to measure
- Patient experience doesn’t equal “patient satisfaction”
- Improvement in culture and process □ improvement in outcomes (Martini Klinik!)
- Patient experience not fully captured by indicators □ critical to also have real engagement with patients
- Participation must be “designed in” at all levels – channels for feedback, structural/institutional paths for involvement
- Public reporting and transparency key to trust

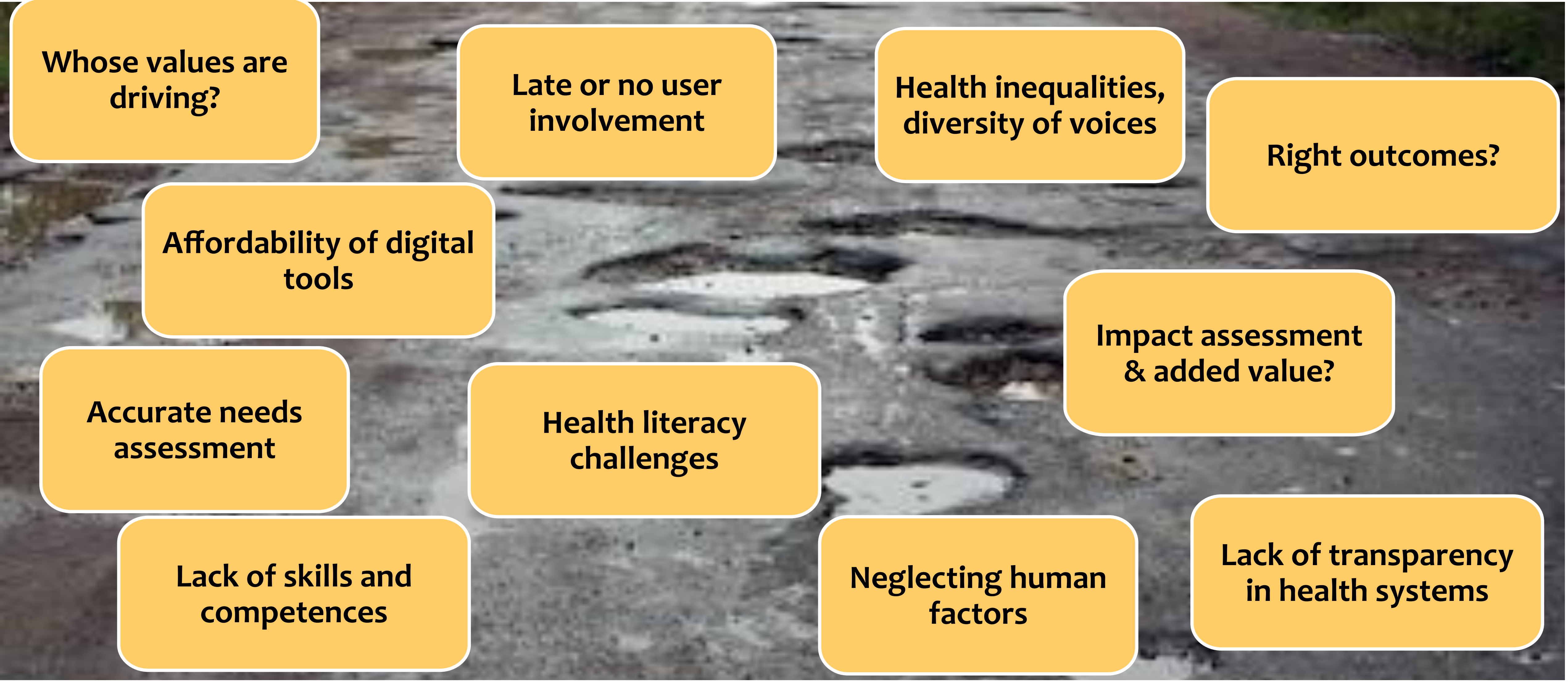
www.eu-patient.eu/globalassets/policy/quality-of-care/quality-survey-report.pdf

Co-creating and implementing digital innovation in health



- Skills are not the only important element
- HCPs, together with patients, should be more involved in the **co-development of digital solutions**
- Through co-creation, digital health solutions can be shaped in a way that is safe and more easily accessible and understandable by both HCPs and patients
- **Digital technology is an underdeveloped area in terms of co-creation**

Common pitfalls and challenges in digital health



Whose values are driving?

Late or no user involvement

Health inequalities, diversity of voices

Right outcomes?

Affordability of digital tools

Impact assessment & added value?

Accurate needs assessment

Health literacy challenges

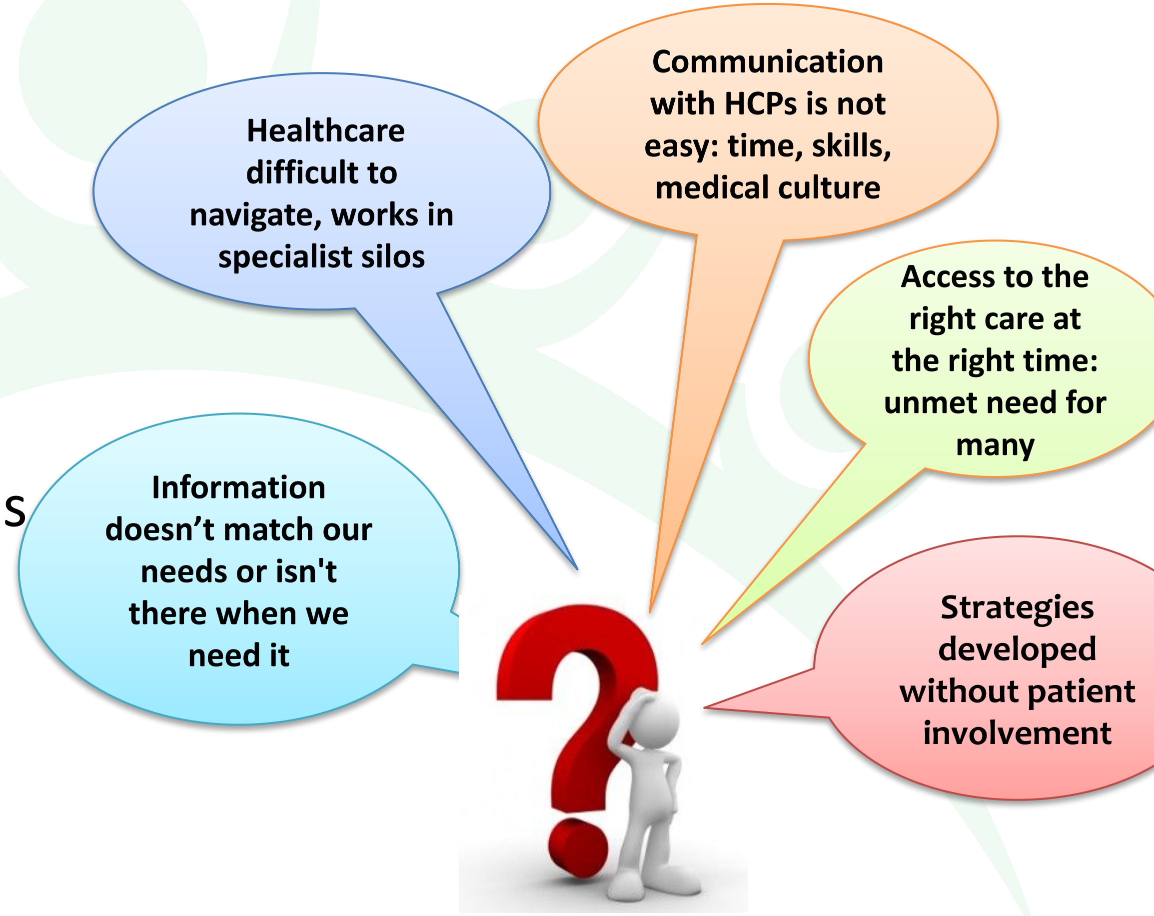
Lack of skills and competences

Neglecting human factors

Lack of transparency in health systems

Chronic conditions challenge professional education

- Chronic diseases need long-term, holistic, integrated management – often of multiple problems
  - One in 4 adults of working age has a long-term health problem or disability
  - 80% of people over 65 have at least one chronic condition.
- Updating the skills of professionals includes skills for effective coordination of care, multidisciplinary teamwork, collaborative care, supporting patients in self-management…



Healthcare difficult to navigate, works in specialist silos

Communication with HCPs is not easy: time, skills, medical culture

Access to the right care at the right time: unmet need for many

Information doesn't match our needs or isn't there when we need it

Strategies developed without patient involvement

EPF Quality Survey (2016)

EPF European Patients Forum

Factors that patients value most in interactions with healthcare are the same across different diseases

- Human relationships at the core
- Being cared for as a person, not only a diagnosis or number
- Being treated with empathy and respect
- Holistic approach: consideration to psychological, emotional social, mental and family aspects of illness together with the physical aspects
- Continuity, not fragmentation
- Good communication & engagement

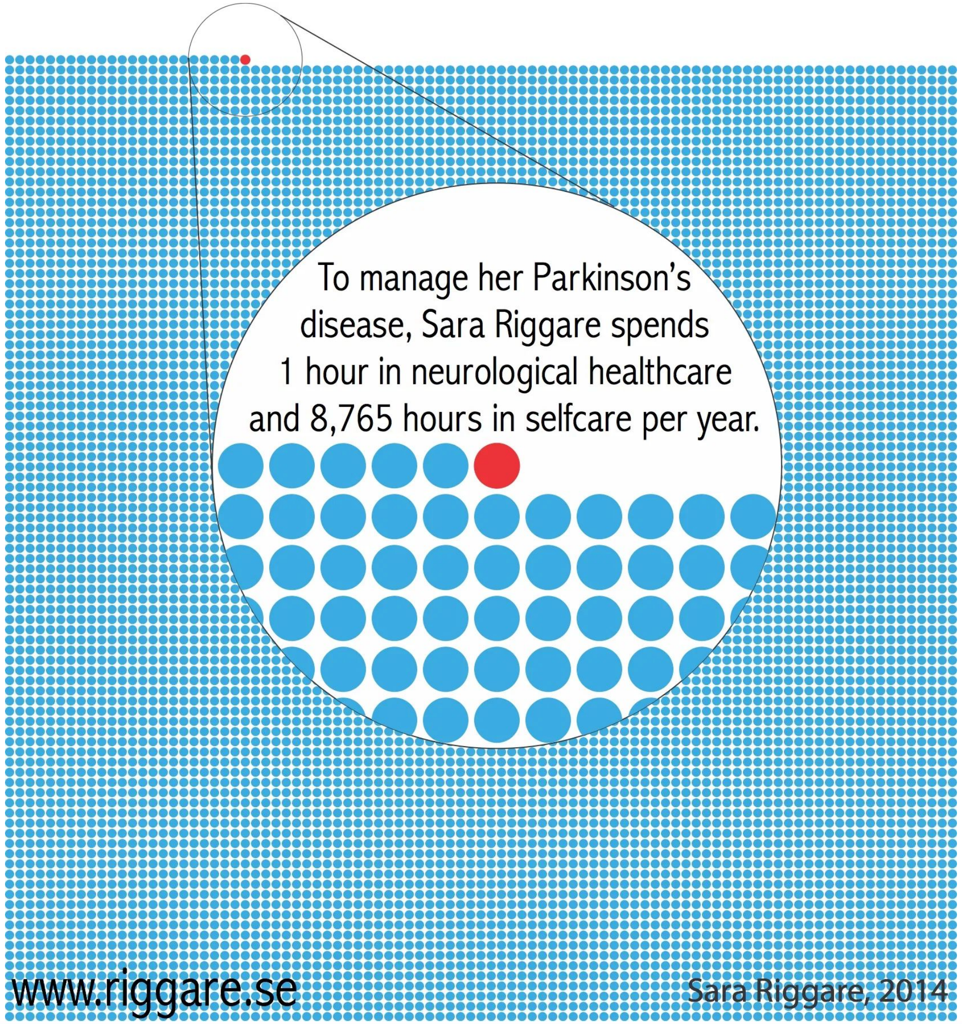
“When doctors and other staff actually listen to what I am saying”

“understand my situation – social and psychological”

“Being helped with the illness in a way that you yourself are an active participant”

www.eu-patient.eu/globalassets/policy/quality-of-care/quality-survey-report.pdf

Patients involvement in HCPs education



- Digitalisation leads to evolving **skill needs** for professionals, creates space for new roles and new ways to interact with patients
- **Professional education** plays crucial role in preparing HPCs for the digital transformation of care
- Surely patient insights are an "added value" to HCP education and should be recognised as such

Concluding reflections

- Partnership with patients is essential to realise the potential of digital technology
- Technology is a tool – not an end in itself
- Patients value the human aspects of care
- Patient involvement in professional education leads to more insights of the patients' experience and perspectives – helping professionals be better at what they do
- Partnering with patients involves sharing knowledge and ultimately sharing power
- Patients and HCPs must be *together* more involved in the design, implementation and evaluation of digital health tools – an under-explored area in healthcare

Thank you for your attention!

From “patient-centred” healthcare

… to participatory healthcare

From ‘doing to’ …
to doing (better) *with* patients,
using digital as a tool

THANK YOU FOR YOUR ATTENTION!

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Spectrum of involvement

- Proposed by Towle et al. (2010)
  - Level 1: Patients' stories -> learning materials
  - Level 2: Simulated / standardized patients involved in teaching, e.g. assessment of communication, history-taking, physical examination skills
  - Level 3: Patients in classroom share their personal experiences of illness and disability and of the healthcare system / students make family/community visits
  - Level 4: Patients actively engaged in a teaching role, either on their own or as co-teachers
  - Level 5: Patients as equal partners also in curriculum development
  - Level 6: Patients at institutional level in educational decision-making, for example about curriculum, student selection, faculty recruitment or program evaluation
- Examples of 5 and 6 are rare

More information?

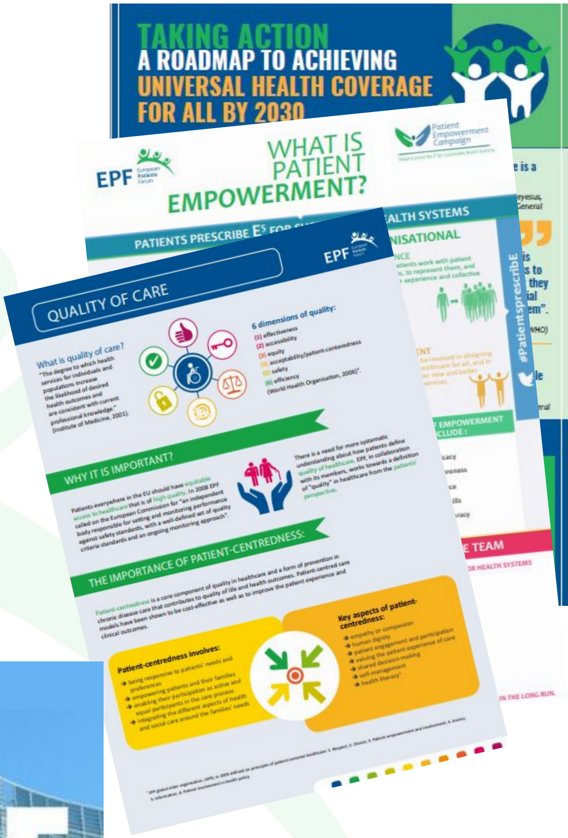
Materials available on our website www.eu-patient.eu

- Survey Report "Patients' perceptions of quality in healthcare" (2016)
- EPF position paper on Quality of care (2017)

- Conference Report "Patient and family empowerment for better patient safety, November 2016
- EPF briefing paper on Patient Safety (2015)
- Proposal on Development of 'Key Competencies' for Patients, Families and Carers in Patient Safety (2017)

- The Patient's Charter on Patient Empowerment (2016)
- Roadmap for Action on Patient Empowerment (2016)
- Briefing paper "Patient empowerment and related concepts" (2015)
- Toolkit for patient organisations on patient empowerment (2017)

- Position paper "Adherence and Concordance" (2015)


TAKING ACTION
A ROADMAP TO ACHIEVING UNIVERSAL HEALTH COVERAGE FOR ALL BY 2030

WHAT IS PATIENT EMPOWERMENT?

QUALITY OF CARE

#EU4HEALTH

Challenges

- Ethical/practical questions
  - Remuneration for patients – views pro/contra
  - Patients are experts but often have extra burdens & costs
  - Challenge to professional power
- Representation
  - Is one patient at the table enough? Danger of tokenism, risk of exclusion of some patient voices
- Investment
  - Meaningful involvement strategy needs investment (e.g. time, extra staff), institutional support & funding
- Preparing patients for participation
  - Capacity-building, training to take on advanced roles in professional education

Expert by lived experience

What is patient empowerment?

“A multi-dimensional **process** that helps people gain control over their own lives and increases their ***capacity to act*** on issues that **they themselves define** as important.”

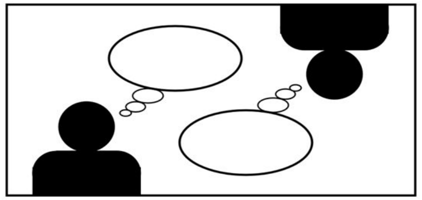
Collectively, “a process through which ***communities*** are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and take political, social, and cultural action to meet those needs.”

(see EPF PE Toolkit)

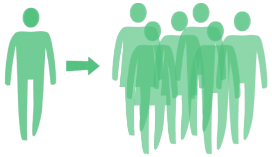
3 Facets of empowerment

- Health literacy
  - Information / education
  - ICT tools
  - Systems navigation…
- Self-management
  - Skills, behaviours, self-efficacy
  - psychological-emotional support…
- Shared decision-making
  - Relationship
  - Decision aids
  - Communication
  - HCP skills, attitudes…

A process: non-binary, non-linear



Cannot be imposed from top-down



Relational, realised in interactions