

What are the latest priorities on digital health at European level and what is at stake with European Parliament Election ?

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@eupatientsforum

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



For a strong European Patient Movement...



Our Vision!

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



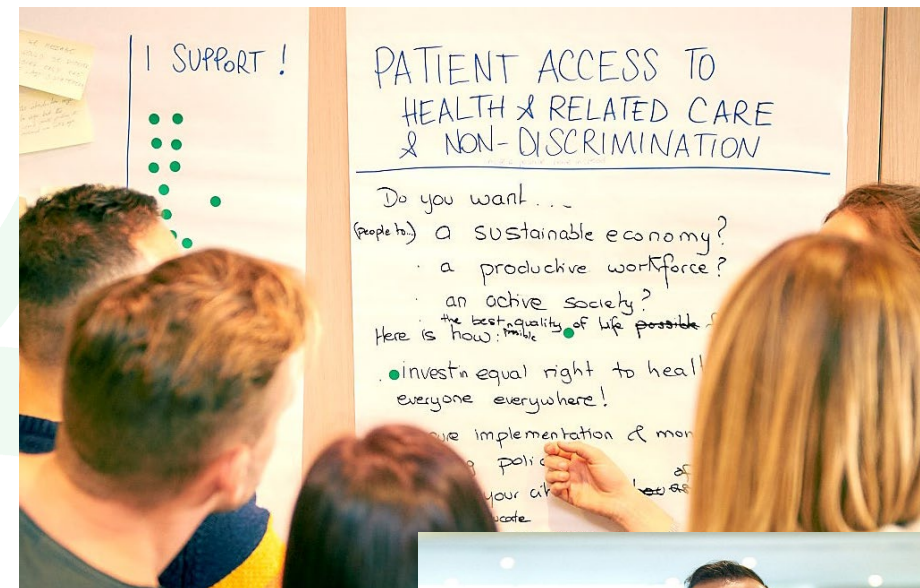
Our Mission!

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

What matters to patients?

The EP elections matter to patients

- EU policies have direct impact on patients' lives
- New EU Parliament and new Commission – in a challenging political environment
 - Including possibly less meaningful EU action on health post-2020
- Patients have seen the concrete benefit of continued EU action in health
 - That is why we drive the #EU4HEALTH campaign
 - We call for strong EU health policy, political leadership, effective coordination and addressing what is important
 - Most EU citizens want “more health in EU and more EU in health”



Patients matter!

Patients' voice matters in the EU elections

- Help policymakers to focus on what is important to people
 - Apply the “What matters to you” conversation to health policy
- Patients and their families = citizens, voters
 - 1 in 3 Europeans aged 15 years + has a chronic disease
 - 2 out of 3 people will have at least 2 chronic conditions at retirement
- Patients are part of civil society & the public health community
 - Showing how patients can make a difference as partners for better policy and practice

EPF's 74 members represent the collective voice of an estimated 150 million people living with chronic diseases across the EU



How we developed our campaign

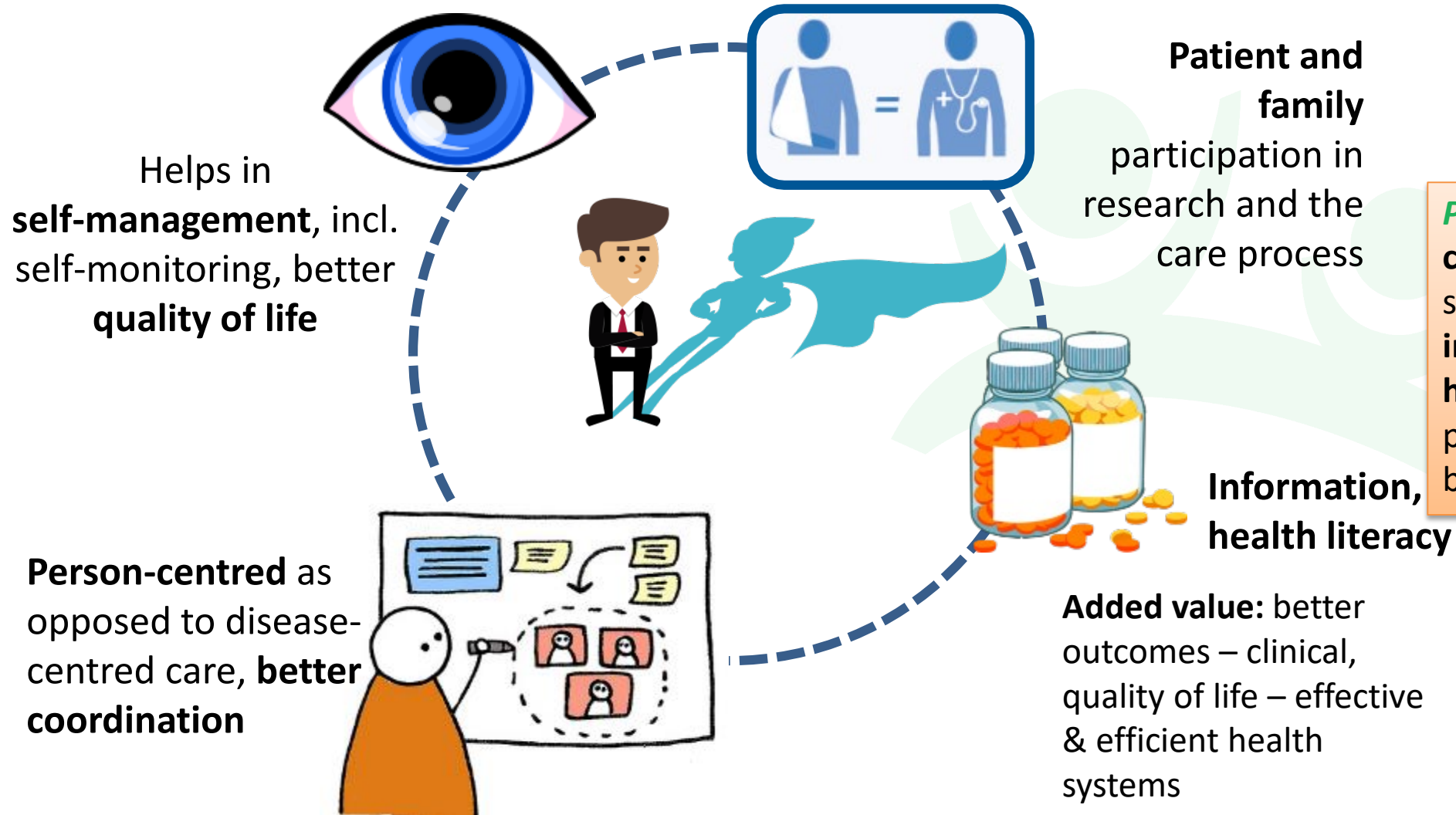
- We identified priorities together with our members – survey & AGM 2018
- These five priorities are based on issues that our members said matter to patients

Five priorities → five key messages

1. Accessing the healthcare we need with no discrimination
2. Being empowered
3. **Driving the development of digital health**
4. Being a partner in driving better research
5. Helping make better health policy



Patients' Expectations of Digital Healthcare

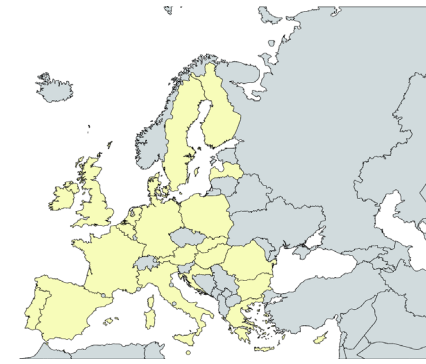


Patients – generally **comfortable** and **willing** to share health-data – **vital importance to advance health research**, help other patients, and ultimately benefit society

What is EPF doing?

| | |
|--|--|
| Working group on digital health | set up to support our work in this area and provide expertise – February 2018 |
| EHDEN | IMI Project – a federated data network enabling access to the data of 100 million EU citizens, standardised to a common data model |
| Digital Health Europe | implementing the Commission’s Communication on the transformation of digital health – patient empowerment |
| Data Saves Lives | A multi-stakeholder initiative to provide ‘state of the art’ information and resources on health data and to create a health data community |
| European Medicines Agency Big Data Report | Contribution and feedback to this report on behalf of EPF (by working group) |
| Commission Recommendation on EHR | Position on the Commission’s Communication and follow-up on involving patients in this work |
| And | Commission’s eHealth Stakeholder group and new upcoming structures; i~HD Task Force on the GDPR implementation; BBMRI-ERIC Stakeholder Forum |

Electronic Healthcare Record survey



What are patients' views and expectations from EHRs?

- Survey in 5 languages – 250 respondents
- Findings:
 - Not only access to EHRs, but an integrated patient portal (booking appointments, follow-ups, reminders, etc)
 - Explaining medical jargon → Accessibility
 - Need for further research: one of the main identified benefits of EHRs is “improving patient/HCP relationships” → How?
 - Ownership, Stewardship

Allowing patients to play a more active role in the management of their health

Ensuring better communication between HCP team and patients

Enabling integrated care pathways and avoiding waste (time and resources)

Improving patient safety (prevent or detect mistakes (e.g. medicines that should not be taken together, inaccurate dosage...),better reporting of side effects or impact of a new treatment)

Informing patients about their health status and treatment

Facilitating cross border healthcare (when you need care in another country)

- Gives an overview of relevant concepts to ensure all EPF members have a “go-to” document as digital health moves forward rapidly
- Different topics, with content, case studies and examples provided by experts but reviewed by EPF members to ensure accessibility
 - Big Data
 - advantages, concerns, use, interaction with other technologies
 - Artificial Intelligence, machine learning
 - main focus of this year’s work – also from the institutions’ side
 - Data privacy, data security, blockchain, real world evidence / data



Digital health inequalities – the risks?

- Digital health inequalities are no different than other social inequalities → robust mechanisms to address them are vital, *but no reason to challenge positive impact of digitalisation*
 - Need to ensure **timely and equitable access** ;
 - **Avoiding discrimination** of patients on the basis of available information;
 - Fundamental values of equity and solidarity need to remain at the core of healthcare systems;
 - Potential initial high investment should be seen in the long-term, value based context

What can health data do?

Health System

Structural changes

Health system strengthening

Patients/HCPs/Health System in general

Prevention

Patient journey/ Quality of Care

Continuity of care

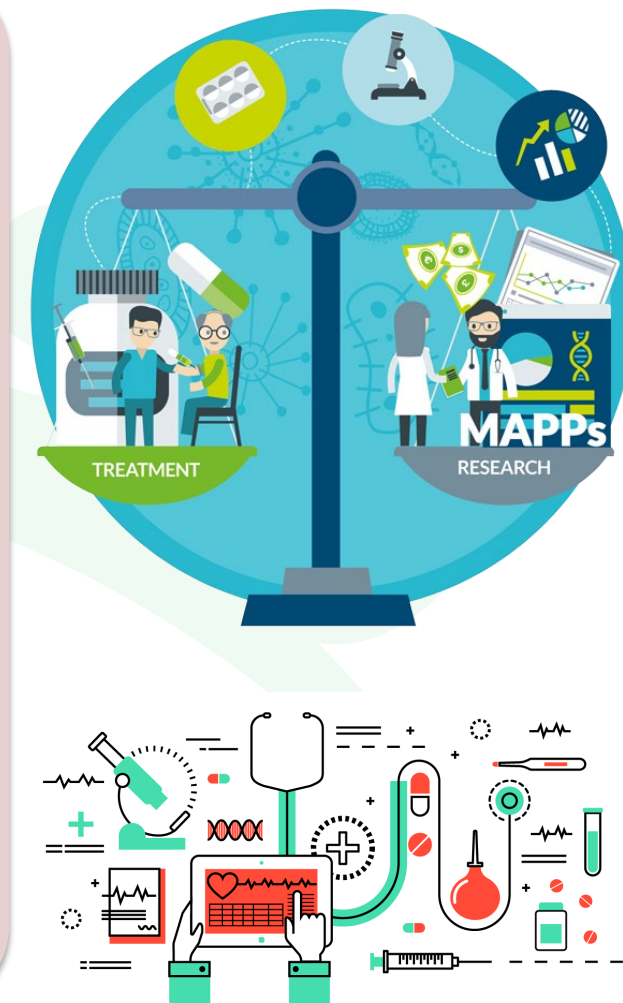
Research

New medicinal products
(pharmacoepidemiology)

Improved existing medicinal
products

(Non) interventional studies

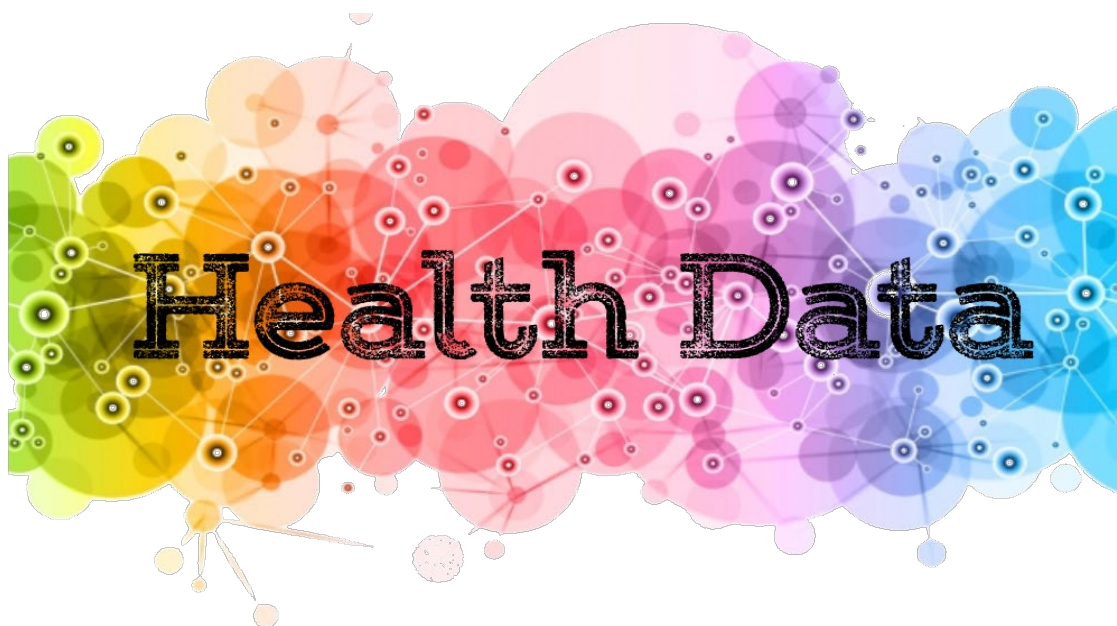
Pharmacovigilance and Real World
Evidence



What is it all about?

- **Vision:**

“a Europe where informed data sharing supports health and scientific research to meet the needs of patients and address the challenges faced by our healthcare systems”



- **Purpose**

“to create a European Health Data Platform that will build awareness and understanding on why data is important; how it is used, and provide a trusted environment for dialogue about the use of health data in Europe”

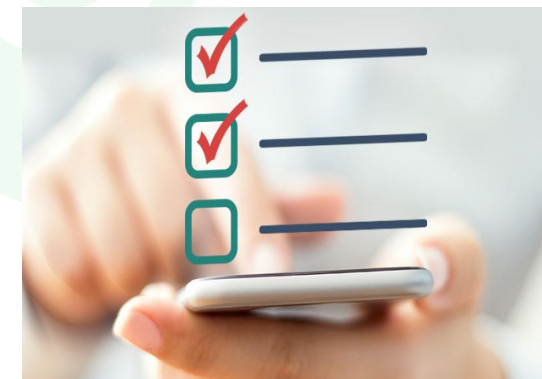
2019 – action points

Web Platform Kick-start by end 2019

Guiding Principles on Health Data

Social media campaign to be launched this year along with events

Continuous interest in engaging stakeholders (including content)



- Digital health offers potential for improving the quality of care
- Patient involvement is crucial in this sphere
 - Engagement with institutions and all stakeholders to achieve this
 - Lessons can be learnt from other sectors
 - Evidence based advocacy (EHR survey is a first step)
- Patient community needs a better understanding of the issues at stake
 - EPF Briefing and Data Saves Lives
- Digital health Inequalities are a potential side-effect, and require appropriate policies and fair practices

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