

HEALTH IN THE DIGITAL SOCIETY DIGITAL SOCIETY FOR HEALTH

16-18 OCTOBER 2017
TALLINN, ESTONIA

Patient Empowerment

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Organised by:



HIMSS Europe

Supported by:



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www.ehealthtallinn2017.ee

ABOUT EPF

- European Patients' Forum
 - Umbrella organisation
 - Active since 2003
 - Independent & non-governmental
 - EU patients' voice
- Our members
 - 74 patients' groups
 - Disease-specific EU & national coalitions



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.”

WHY PATIENT EMPOWERMENT?

- Chronic disease challenge: requires a fundamental shift to a **patient/family-centred** approach
- **Self-management** with well-integrated professional support
- Need for **patient empowerment** – patient as the “most important member of their healthcare team”
- Need for **patients’ participation** at every level in the health system – also in (re)designing and evaluating services!



“The people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare.”

Alma Ata Declaration – Principle IV (1978, WHO)

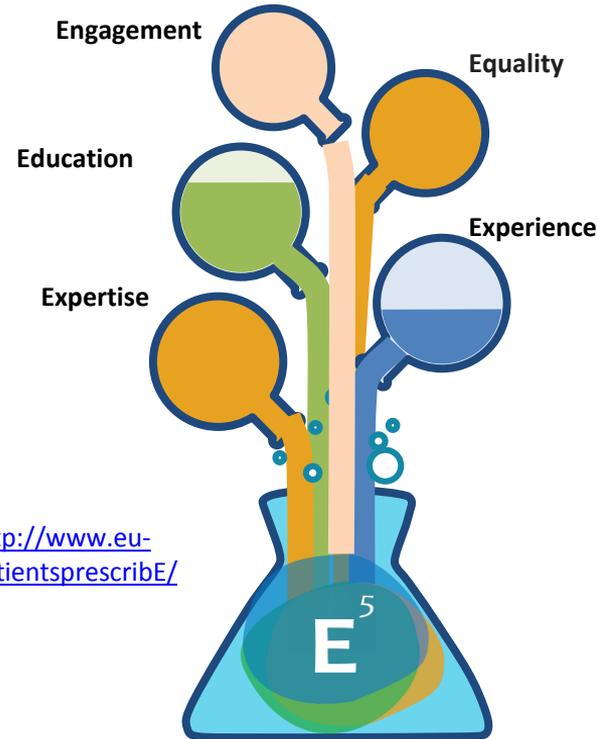
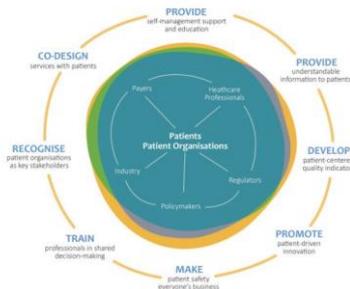
Vision: patients as
“co-producers” of
well-being

CAMPAIGN ON PATIENT EMPOWERMENT

- 01 Education.** Making informed decisions with the right information and support.
- 02 Expertise.** Patients' unique expertise derived from lived experience is a valuable resource.
- 03 Equality.** Equal partnership between patients and professionals.

04 Experience. Patients' organisations channel the patient community's collective voice.

05 Engagement. Patients as well as the whole society for better health services and policy.



Link to the campaign: <http://www.eu-patient.eu/campaign/PatientsprescribeE/>

DO PATIENTS WANT TO BE MORE EMPOWERED?

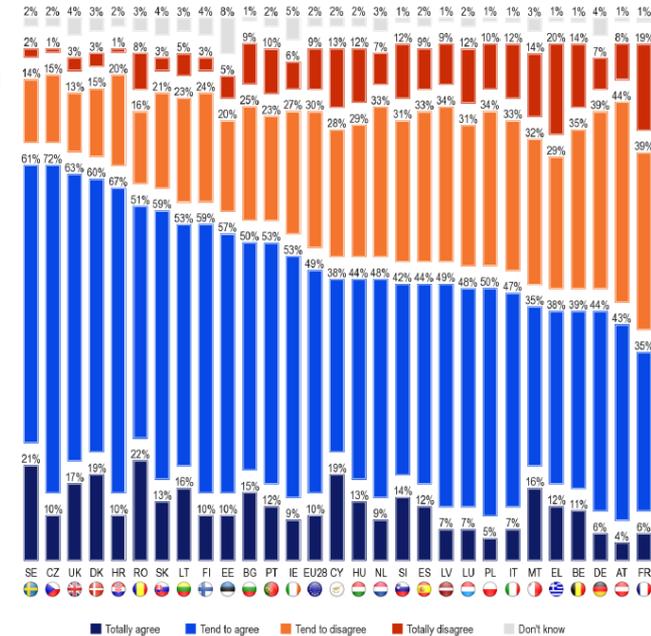
- 92% of patients are willing to play a more active role in managing their own condition
- 60% of patients (and 70% of HCP) would be willing to use eHealth in the short-medium future
- ... but only 48% think they are ready to handle the additional responsibilities presented by eHealth
- Similar trends for HCPs

YES,
please.

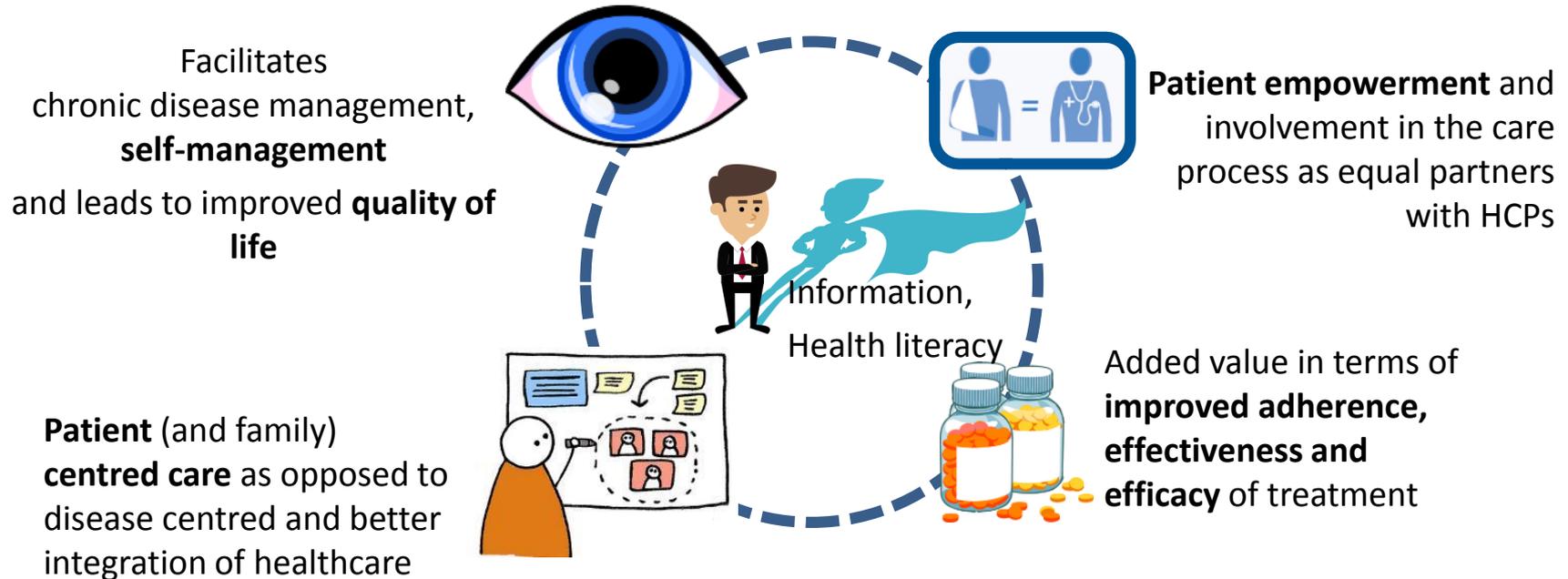
60%



Q21.7. For each of the following statements please tell me whether you totally agree, tend to agree, tend to disagree or totally disagree. You trust the information from the Internet to make health-related decisions



PATIENT EXPECTATIONS OF DIGITAL HEALTHCARE



EPF'S WORK ON DIGITAL HEALTH

Position Statement

on the EC's proposal for a **General Data Protection Regulation** – *December 2012*

Position Statement

on **informed consent** in **clinical trials** – *May 2016*

Guide for patients' organisations

The new EU Regulation on the protection of personal data: what does it mean for patients? – *Autumn 2016*

Position Paper

on **eHealth** - *December 2016*

Reply

to the **public consultation on Transformation of Health and Care in the Digital Single Market** – *October 2017*

Briefing on big data

aim of ensuring the capacity of patient communities to provide meaningful input to policy discussions in this highly technical area – *December 2017*

Patient survey

on **electronic health records** and **data sharing** – *2017-18*

EMPOWERING PATIENTS ON DIGITAL HEALTH

Digital health has been a policy priority for EPF over the last 7 years with the following objectives:

1. To acquire thorough understanding of **patients' needs and perspectives** on digital health
2. To ensure that **digital health services** are designed, assessed, and implemented in a **patient-centred way** and ensure that **eHealth policies and programmes** effectively enable and **promote patient-centeredness**.
3. To ensure that implementation of digital health services is accompanied by strategies for strengthening **health literacy** and **patient empowerment**

Right of Access to one's own data:

- Key component of PE and patients' health literacy
- in EU still obstacles for patients to access their health information
- and data stored in silos rather than in interoperable systems

Right to information:

- Transparent policies in place
- Informed consent
- Information about their right as data subjects

Right to be forgotten/ to object/ to rectification

Any restriction to these rights should be limited and justified

CONCLUSIONS

- Empowerment has 3 facets
 - Health literacy
 - Shared decision-making
 - Self-management
- Digital aspects can be an enabler for patient empowerment
 - but, always taking into account:
 - The individual patients' wants and needs
 - Privacy concerns



from “to the patient”...



... to “with the patient”

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THANK YOU

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