

Patients' Perspective on the EHDS

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Health systems in digital transition
Towards a European Health Data Space, 22/11/2021 (Brussels)



@eupatientsforum

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



About EPF – European Patients' Forum



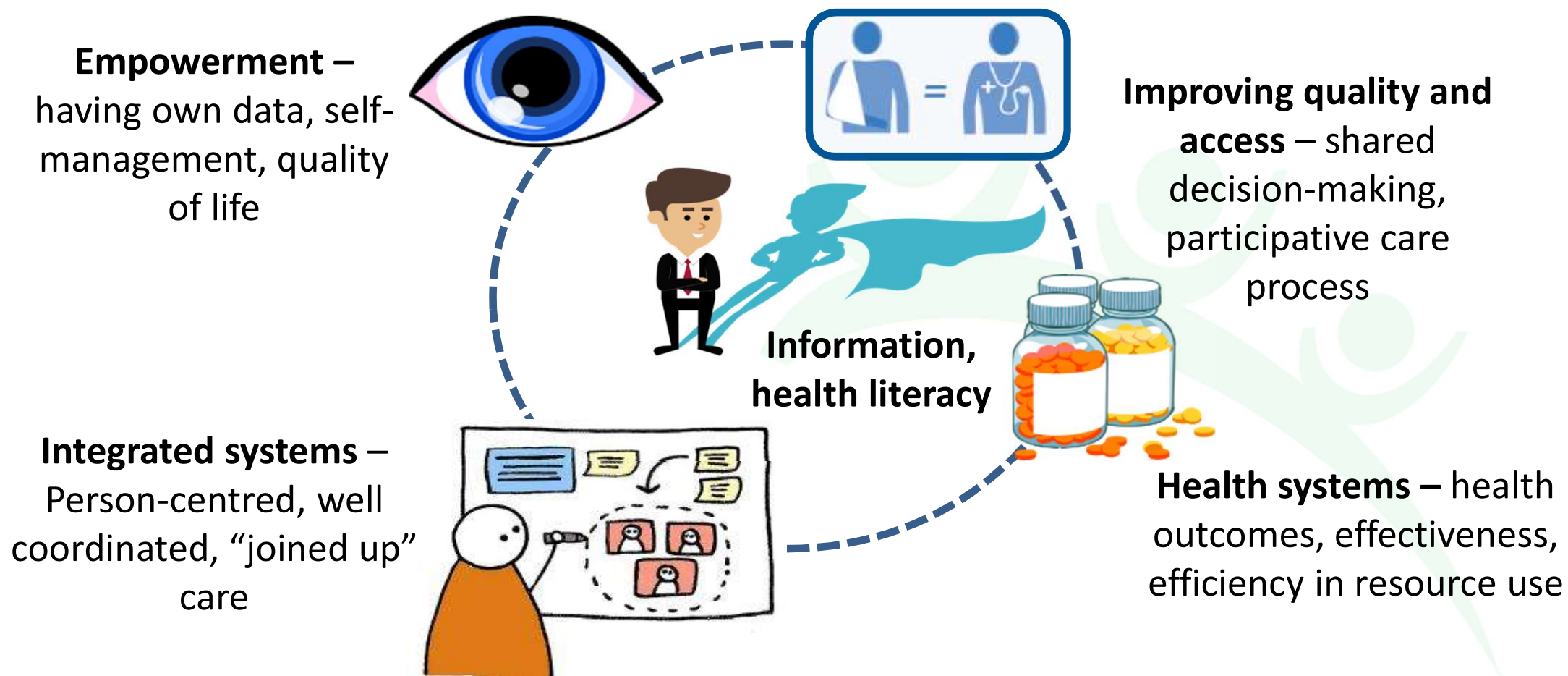
Who we are

- Set up in 2003, based in Brussels
- Independent NGO
- Pan-European, cross-disease umbrella patient organisation
- **77 members** – National level non-disease specific and EU level disease specific organisations



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What is the value of digital health for patients?



Health data in a COVID and post-COVID world



- The **pandemic accelerated the deployment of digital health solutions** and proved the importance of **health data** in managing cross-border health emergencies
- However, it also highlighted some of the current **shortcomings and issues**
 - **Scarce interoperability and lack of common health data definitions and frameworks**
 - Digital health accessibility **shortage**
 - Ad-hoc innovation approach rather than **systematic evaluation** and implementation
 - **Concerns about tracing apps** – trust, data protection, privacy, accuracy, lack of trust
 - **Questionable use of data** for research leading to potential large impact on people's health

Data and AI for health science: what way forward?

- Health systems should therefore learn from the **COVID-19 crisis**, to keep the momentum in positive adoption of technology while taking into account the lesson learned and the shortcomings
- Digitalisation is high in EPF and in the EU agenda:
 - Health data and European Health Data Space
 - Artificial Intelligence



EPF vision for a patients-centred health data revolution



Patients need to be in control of their data



Ensure meaningful informed consent mechanisms



More inclusive and user-friendly data-based applications and products



Safer data for better healthcare and the public interest



Better data for safer and better AI



Health literacy and patients' empowerment to realise data-driven innovation in healthcare



A patient-centred **European Health Data Space**

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Shaping a EHDS with and for patients – our views



ENSURE **BARRIER-FREE ACCESS AND CONTROL OF HEALTH DATA** IN AN EASY AND TRANSPARENT WAY, WITH THE HIGHEST POSSIBLE LEVEL OF DATA PROTECTION AND BASED ON CONSENT



ENSURE **PATIENT SAFETY** AT ALL LEVELS



DELIVER **HARMONISATION** WHILE KEEPING IN MIND THE DIFFERENCES BETWEEN DIFFERENT HEALTH SYSTEMS

<https://www.eu-patient.eu/news/latest-epf-news/2021/shaping-a-european-health-data-space-with-and-for-patients/>

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Shaping a EHDS with and for patients – our views



TAKE INTO CONSIDERATION AND TACKLE CURRENT AND POTENTIAL **INEQUALITIES AND GAPS** IN HEALTH LITERACY AND ACCESS TO DIGITAL



TACKLE THE **ETHICAL AND PRACTICAL CHALLENGES** LINKED TO CURRENT AND FUTURE DIGITAL HEALTH TRANSFORMATION



FOSTER A **DIGITAL TRANSFORMATION OF HEALTHCARE** THAT DELIVERS ADDED VALUE FOR PATIENTS AND RESPONDS TO THEIR TRUE NEEDS AND CONCERNS



INVOLVE PATIENTS IN A CONCRETE AND MEANINGFUL WAY IN ITS **SHAPING, GOVERNANCE AND IMPLEMENTATION**

<https://www.eu-patient.eu/news/latest-epf-news/2021/shaping-a-european-health-data-space-with-and-for-patients/>

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In conclusion – EPF recommendations



- Health data have the **potential to transform healthcare** and have positive impacts for patients. **Such benefits should be clear and accessible to all patients.**
- **Expectations and challenges** need to be managed and addressed
- The EHDS represents a key chance to **shape the future health data in Europe** and it must be done **involving patients at all level**, from innovation development to policy-making. A journey together, with and for patients.
- **Trust and acceptance of the EHDS will be key to shape a successful initiative**
- A European framework on health data should focus on a fit-for-purpose **policy framework**, data **access and control**, **health literacy**, equitable and connected **infrastructures and platforms**, uptake of **best practices and current initiatives** to **facilitate movement of patients' and their data** across the EU.
- Patients need **trustworthy, ethical, safe, and inclusive data sharing and artificial intelligence** in healthcare to **support professionals** and researchers in delivering better care



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EPF Congress – Digital transformation of healthcare



2022 EPF Congress

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TO CONTINUE THE
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THE DIGITAL
TRANSFORMATION OF
HEALTHCARE

More info on epfcongress.eu

21-22 April 2022

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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

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