

# Patients' Perspective on the EHDS

Michele Calabro'  
Policy Adviser  
European Patients' Forum

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



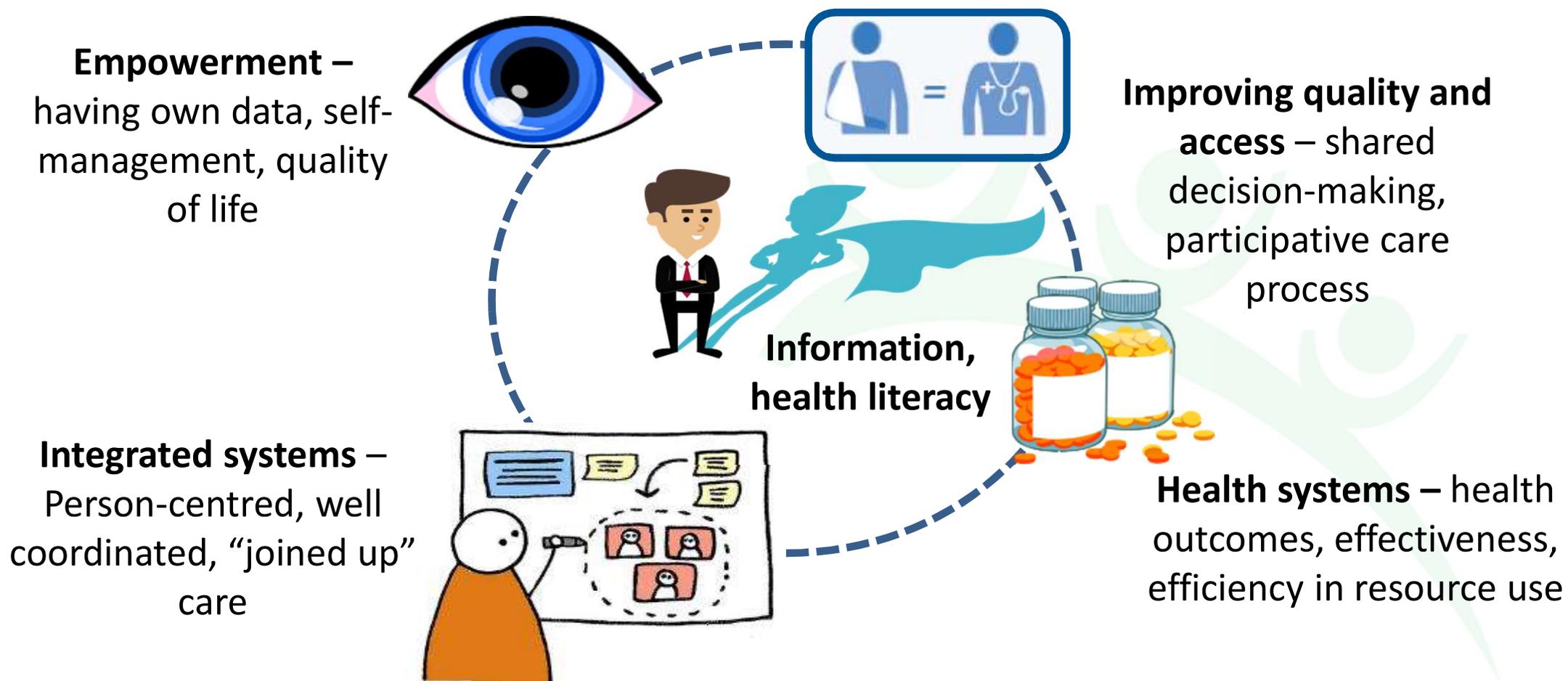
## Who we are

- 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



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

# 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



Safer data for better healthcare and the public interest



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



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



Better data for safer and better AI



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

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

# 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/>

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

# 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/>

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

# 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



# EPF Congress – Digital transformation of healthcare



## 2022 EPF Congress

JOIN US IN BRUSSELS  
TO CONTINUE THE  
CONVERSATION ON  
THE DIGITAL  
TRANSFORMATION OF  
HEALTHCARE

More info on [epfcongress.eu](https://epfcongress.eu)

21-22 April 2022

[PRE-REGISTER NOW](#)

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

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!

Follow us on Social Media!



/europeanpatientsforum



/eupatient



/eupatientsforum



eu-patient.eu/blog

**More information**

[www.eu-patient.eu](http://www.eu-patient.eu)

[info@eu-patient.eu](mailto:info@eu-patient.eu)

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