## PATIENTS' PERSPECTIVES ON USE OF THEIR DATA

Laurène Souchet, EPF Policy Officer

27.01.2015

Brussels

## **G** A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE



#### – 64 member organisations

**OUR MEMBERS:** disease-specific EU & national coalitions

#### A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

- Independent, non-governmental umbrella organisation set up in 2003
- **OUR VISION: All** patients with chronic or long term conditions in the EU have **equitable access** to high quality, patient-centred health and social care
- OUR ROLE: To ensure the patients' community drives policies and programmes that affect patients' lives





## **About the European Patients Forum**



- Patients' fundamental right to protection of their data is vital in diverse contexts: *healthcare, eHealth, cross-border care, clinical trials,...*
- Fear of discrimination on the grounds of health/genetics: in the field of employment, insurances
- New technologies offer opportunities to collect, use and share health data more efficiently

... but set new challenges for privacy and data security

# Patients want to share their data for research

- Patients recognise that the sharing of their data is of vital importance to advance health research and help other patients, and ultimately benefit society
- Changing role of patients:
- ✓ informed and engaged actors
- ✓ a source of expert information
- ✓ Participating in research
- ✓ Leading research

#### **Getting the balance right!**



"You have to learn about thousands of diseases, but

I only have to focus on fixing what's wrong with ME! Now which one of us do you think is the expert?"



#### 🕻 A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE 🥊

## Informed consent: a key principle

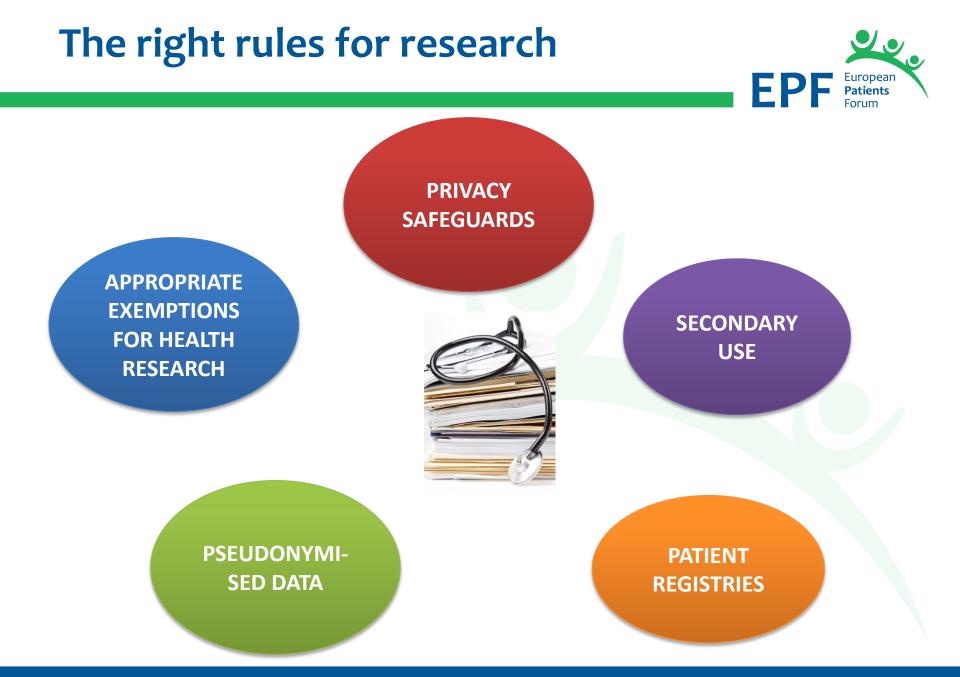
## Right to informed consent for use of health and genetic data :

- large disparities in informed consent across the EU
- For research it should be as a rule required
- EPF has developed recommendations for meaningfully informed consent: EPF statement on clinical trials-
- Secondary use of data: Patients should be informed









**66** A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE **55** 

## The DatamattersEU campaign





**The European Data in Health Research Alliance** - *ensuring the Data Protection Regulation allows vital research to continue.* 





www.datasaveslives.eu

**A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE** 

## **Empowering patients**

#### **Right of Access to one's own data:**

- in EU still obstacles for patients to access their health information
- and data stored in silos rather than in interoperable systems
- Right to access results of clinical trials www.alltrials.net

## **Right to information:**

- Transparent policies in place
- Informed consent



FD

• Information about their right as data subjects

#### 🔓 A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE 🤧

## Our data, our privacy, our health: Involve patients!



- Patient participation in decisions regarding health and genetic data is a matter of good governance.
- Involvement at policy and programme level on questions of privacy in healthcare and health research

### Beyond this, need for meaningful involvement in research

- The patient community has developed tools to enable this:
- For research partners : PatientPatner, Value +
- > For patients and their organisations: EUPATI

It is the patients' data, their privacy, and their health that is at stake!

#### 🖌 A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE 🤧





- Patients' role has changed over the last decades
- Empowering patients as owner of their health and genetic data to make decisions about their personal information
- Need for clear information and direct involvement in data management
- Patients are willing and able to contribute!



🔓 A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE 🤧

## **THANK YOU FOR YOUR ATTENTION!**

Follow us on Social Media!



/europeanpatientsforum





/eupatientsforum



eu-patient.eu/blog

More information www.eu-patient.eu info@eu-patient.eu

A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

