

PATIENTS' PERSPECTIVES ON USE OF THEIR DATA

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

About the European Patients Forum



- 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
- **OUR MEMBERS:** disease-specific EU & national coalitions – 64 member organisations



- 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



“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?”

Getting the balance right!

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



The right rules for research

PRIVACY SAFEGUARDS

APPROPRIATE EXEMPTIONS FOR HEALTH RESEARCH

SECONDARY USE

PSEUDONYMISED DATA

PATIENT REGISTRIES



The DatamattersEU campaign



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



#DatamattersEU



www.datasaveslives.eu

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
- Information about their right as data subjects



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 : PatientPartner, Value +*
 - *For patients and their organisations: EUPATI*

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

- 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!



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