PATIENTS’ PERSPECTIVES ON USE OF THEIR DATA

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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’ privacy concerns

• 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
The right rules for research

- Appropriate exemptions for health research
- Privacy safeguards
- Secondary use
- Pseudonymised data
- Patient registries

"A strong patients' voice to drive better health in Europe"
The European Data in Health Research Alliance - ensuring the Data Protection Regulation allows vital research to continue.

I trust health research to use my data for society’s benefit

#DatamattersEU  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
• 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: PatientPatner, Value +
  ➢ For patients and their organisations: EUPATI

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

• 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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