

# Sharing data, collaborating and coordinating across the continuum of care

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@eupatientsforum

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

**EPF**   
European  
Patients  
Forum

# EPF's work on Digital Health

## Position Statement

on the EC's proposal for a **General Data Protection Regulation** – *December 2012*

## Position Statement

on **informed consent in clinical trials** – *May 2016*

## Guide for patients' organisations

**The new EU Regulation on the protection of personal data: what does it mean for patients?** – *Autumn 2016*

## Position Paper

on **eHealth** - *December 2016*

## Reply

to the **public consultation on Transformation of Health and Care** in the Digital Single Market – *October 2017*

## Briefing on big data

aim of ensuring the **capacity of patient communities** to provide meaningful input to policy discussions in this highly technical area – *December 2017*

## Patient survey

on **electronic health records and data sharing** – *2017-18*

# Distinction between *patients* and citizens

**Patients** – generally **comfortable** and **willing** to share health data and recognise that this is of **vital importance to advance health research**

- **Trusted environment** – healthcare and research setting
- To help peers – general community and **peer support**
- To help **future generations**
- Looking for **solutions to unmet needs**
- Have lived through the **experience of diagnosis** and hospitalization and home care
- Have already **experienced** the benefit of research, through therapy or management of their disease
- Patients learning from their own data - **self-management, empowerment**

**Patients** have **privacy** and **data security concerns**

- **Unauthorised disclosure** of personal health or genetic information could **negatively impact** on an individual patient's personal and professional life, this is why **informed consent** and **transparency** on the use made of data is essential.



THANK YOU



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