**Campaign on Data Protection**

**Background**

EPF has been approached by the WellcomeTrust, a global charitable foundation dedicated to achieving improvements in health, who would like to launch a common campaign around the EU Data Protection Regulation with patients and other non commercial research organisations.

The proposal for a Regulation on the protection of personal data is currently discussed at EU level. Its rules apply to all sectors including health and research. The European Parliament adopted in March a 1st reading position for stricter rules on consent for research that lack flexibility, may lead to more fragmentation of data protection rules in Europe, and that are likely to be burdensome for research projects, biobanks and patient registries if adopted.

**What is the aim of this campaign?**

The aim of this campaign is to ensure decision makers in the Council and the European Parliament understand the importance of having Data Protections rules that facilitate research, and to show that patients and researchers have the same concerns and are united on this question. It will center around the message that patient want to share their data for health research, and that there are existing safeguards to protect patients‘ rights in research.

**What will the campaign look like?**

Together we will build a website platform that will host the campaign with strong images showing patients who say that we agree to share our data to benefit health research and even that we trust health research to use our data for society‘s benefits. We will mainly use social media to catch officials from the three EU Institutions‘ attention and lead them to the website.

**Why is it important for EPF?**

Ensuring the right rules and exemptions are in place for research is essential not to delay or make impossible research projects that could benefit patients. It is also important to raise awareness of EU decision makers that patients value the possibility to share their data for scientific research (including public health, social science and medical research). It will also show patients take an active role on research issues and an opportunity to build stronger relationship with non profit research organisations.

Safeguards are in place to ensure that researchers treat patients’ data with respect and respect patients’ right to privacy/confidentiality.