



## **WORK PACKAGE 1: EUROPEAN PATIENT RESEARCH PRIORITIES**

(Update July 2018)

### **Background**

Patient active involvement in clinical research (“experimenting with” as opposed to “experimenting on” patients) makes research more accountable and transparent, leads to better results and generates research that is more relevant to patients. The Patient-Centered Outcomes Research Institute (PCORI) in the USA and the James Lind Alliance in Europe have outlined the differences in research priorities between doctors and patients and instituted measures to ensure that patients participate in the whole research process. Therefore, it appears crucial that CF Patients Organizations in EU organize local initiatives aimed at defining research strategies that involve patients’ and relatives’ needs. The local groups, to converge later in an EU-based single group, may have the following goals: a) To establish a connection/relationship between the patients and their relatives’ world and the scientific world, by identifying research topics close to the true needs of CF people; b) To turn the patients’ needs into suggestions expressed in scientific and programmatic terms; c) To highlight, interpret and understand the priorities expressed by patients and to propose them to research funders.

### **Aims**

The overall purpose, patient’s empowerment in CF, passes through the definition of research strategies that involve patients and relatives and consider their real needs. This objective, in turn, needs strengthened knowledge of the research methodology by patients and relatives, having at the horizon the perspective to use the acquired methodology to promote the development of future studies and to disseminate the best practices, processes, and methods for patient involvement in research topic generation in Europe.

### **Activities**

- Representing the needs of the stakeholders at the national/international meetings where research strategies are discussed and selected.
- Participation in working groups on the reports, posters and social media.
- Working on patients’ research priorities.

### **Deliverables**

- Publication of the most desired research objectives ranked in order of relevance and importance for the stakeholders.
- Identification of a restricted group of stakeholders (patients and relatives) who have undergone a specific formation toward the figure of expert informed patients/relatives with knowledge of both the mechanism of the disease and the mechanisms of international research.
- A survey among the CF Europe member organizations to report the strategies used to involve patients in clinical research.

### **Countries involved**

Italy, Belgium, France, Netherlands, Luxembourg, Switzerland, UK, Germany.



### **Workpackage leaders**

Luigi Graziano (Italy), Paola De Carli (France).

### **Budget**

To be updated through the survey on patient engagement in clinical research among CF Europe member organizations.