

# European Patient Organizations in Knowledge Society (EPOKS)

<https://neurodegenerationresearch.eu/survey/european-patient-organizations-in-knowledge-society-epoks/>

## Title of project or programme

European Patient Organizations in Knowledge Society (EPOKS)

## Principal Investigators of project/programme grant

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France

## Source of funding information

European Commission

## Total sum awarded (Euro)

905242

## Start date of award

01-02-2009

## Total duration of award in months

36

## The project/programme is most relevant to

- Alzheimer's disease and other dementias

## Keywords

gender,governance,medicine,health,knowledge,patient,organization,europeanisation,policy-making

## **Research abstract in English**

The last two decades have witnessed the increasing role of patient, user and civil society organizations (POs and CSOs) in the production of knowledge on diseases and health problems. Rich and detailed studies have shown that this phenomenon entails new forms of activism. It also questions the modes of governance of knowledge, as well as the role of knowledge in the governance of health and medical issues. Does lay knowledge stand on an equal footing with expert knowledge? How do different stakeholders in the domain of health and medicine consider experiential knowledge brought to the fore by POs and CSOs? So far, research on POs and CSOs involvement into the production of knowledge has mainly focused on case studies.

Few comparative studies across national contexts and condition areas are available. This is where EPOKS seeks to make an original contribution. It aims at deepening the understanding of similarities as well as differences between national organizations in France, Portugal, the U.K and Ireland, active in four conditions areas. These are the fields of rare and orphan diseases, childbirth issues, Alzheimer s Disease, and ADHD (Attention Deficit and Hyperactivity Disorder). EPOKS will investigate and compare the modes of interaction and cross-fertilization between different forms of knowledge across these national contexts and condition areas. EPOKS will also address an important phenomenon that has received little attention until now: the multiplication of European coalitions of POs and CSOs in the domain of health and medicine. Very little is known on the types of organizations that these European coalitions actually constitute.

## **Lay Summary**