



## EPPOSI 2021

### A new strategy of renovation and renewal for patients, science and industry

(to be reviewed during next strategy meeting feb-march 2016 in Brussels)

The European Platform for Patients' Organisations Science and Industry - EPPOSI - has been working hard in 2015 to come back from a difficult phase in which it could be argued that the organisation lost its way and suffered financial difficulties.

Under new management fully supported by the current and former presidents, vice-presidents and board members, the organisation is regaining its direction and voice in the health policy in European policy making and the Member States. This document is both a description of where we are and where we are going and an invitation to (re)join us in rejuvenating the organisation. In our new strategic period, EPPOSI would like to ensure that we coordinate a platform for patients, ICT, pharmaceutical and medical technology companies, investors, private and social insurers and healthcare providers that operates in the best interests of patients.

As a part of our continuing strategic development and membership outreach, we would like to invite you to a meeting of interested stakeholders to help shape the future of the platform:

Location: EPPOSI offices 38/40 Square de Meeûs, 1000, Brussels, Belgium

Date: TBC

Please RSVP to [secretary.general@epposi.org](mailto:secretary.general@epposi.org) or phone: +32 (0)2 401 68 18

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### EPPOSI 2015: Recent and Current Projects

#### **Rapid Health Technology Assessments and HTA/Access to Market/reimbursement**

The keystone of the new EPPOSI strategy is the introduction of Rapid Health Technology Assessments (RHTA). In the Member States, local chapters of EPPOSI are steering the common agenda of increasing patient-stakeholder involvement in decision making through a digital health ecosystem. Within this system, mHealth sensors collect validated patient data – in which the literacy and the frailty of the patient are also recorded - to inform the RHTAs about the burden of disease 24 hours a day, 7 days a week. Not only will this system drastically cut down on the length of time needed to undertake a traditional HTA, it also decreases the amount of unnecessary information generated by the lengthy review process.

Rapid HTA can be applied to drug development as well as medical devices and drug-device combinations and will serve to safely hasten products to market at the same time as increased

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patient participation in the process. By retaining the intellectual property rights over their data that is shared with RHTAs, patients are additionally empowered to be able to use it in other ways when needed. EPPOSI is also currently exploring collaboration with insurers to work out how data and services could be exchanged in reimbursement systems for example.

Through the involvement of individual Member State representatives, as well as Industry and Patient Stakeholders of EPPOSI, RHTA evaluated technologies are used in effective cross-border projects involving patient-consumers across EU Member State Borders. The projects involve post-hospital care support, cardiological monitoring, including data processing from previously un-interoperable systems across the EU

EPPOSI is fully intending to work in collaboration with existing stakeholders working on access and HTAs and is already working with the Patient Access Partnership (PACT) and the European Alliance for Personalised Medicine (EAPM). We are also intending to reconnect with EUnetHTA and the EPPOSI president represents both EPPOSI and the World Federation of Incontinent Patients on the European Forum for Good Clinical Practice (EFGCP). EPPOSI is also a member of the MedTech EU joint Working Party, aimed at promoting ethical and quality standards for the clinical development of medical technology

### **Biobanks**

EPPOSI has successfully entered into a contract with BBMRI-ERIC for a project where EPPOSI will add value as the multi-stakeholder advisory group. The details of the project are currently being negotiated between the EPPOSI President and BBMRI-ERIC.

### **Digital ehealth, mHealth, Telemedicine Interoperability, Standardisation and Governance**

EPPOSI is poised to play a crucial role in providing solutions for the current issues of interoperability within the EU. Creating well managed interoperable electronic health systems through harmonised electronic health records for optimum cross-border care and quality Rapid HTAs will go a long way to strengthening interoperability in the EU. Current EPPOSI projects also include post-hospital care support in cardiological monitoring using data processing techniques from previously un-interoperable systems across the EU.

EPPOSI is a member of the European Commission's mHealth Stakeholder Forum, in particular the working group on mhealth Apps and software and is considering joining the new working group on mHealth assessment guidelines. The EPPOSI Secretary General has just become a member of the Trillennium Bridge Project which extends the European Patient Summaries and Meaningful Use II, Transitions of Care in the United States to establish an interoperability bridge that intends to benefit EU and US citizens alike.

### **Self-care Barometer**

The Self Care Barometer, the first of its kind, will provide a benchmark for future surveys, allowing us to track trends citizens' attitudes and interest for self-care. Under the old plan, the research will be conducted every two years; it will be now up to the new team and members to decide if this continues in such a way. The Self Care Barometer showed that there is a public appetite for self-care.



However, new policies are needed to support citizens' use of self-care, including increasing health literacy and improving access to information and expertise. Used well, self-care can help to unlock the benefits of disease prevention, early intervention and self-management. It also taps in to a growing trend for taking personal responsibility for personal health and well-being.

### **Neo-natal Screening**

Epposi's Rare Disease Interest Group undertook a critical literature review to map and identify key gaps in the current decision making processes and ethical considerations on systematic neonatal screening programmes in Europe with an emphasis on the involvement of families and patients' representatives. The study found that ethical consideration of the decision making process relating to new-born screening programmes is an important factor both on policy level and on the family level. On policy level, issues like cost effectiveness and preventing possible discrimination are important elements. Several studies have suggested that a better information provision including information about possible false positive/negative results is needed for the families to enable informed decision making.

### **EPPOSI '21**

Looking forward to the next strategic period of 2016 to 2021, the new EPPOSI team have been laying the ground for working with interested partners and members to develop our strategy. In order to achieve our aim of placing patients at the heart of healthcare and data management, we have been connecting with industry, other patient groups and ICT companies in the first instance, and plan to build new relations with insurers and healthcare providers in the near future. Anyone who is interested in placing patients at the heart of their healthcare is welcome to start a dialogue with EPPOSI.

### **Concrete Next Steps**

Given the vital importance of IMI and other EU industry funding partnerships in shaping and defining the future of European pharmaceutical and medical devices research, EPPOSI has been analysing all the current and future calls within IMI and Horizon 2020. In collaboration with multiple stakeholders, we would like to identify and prioritise future areas of work for the organisation that may or may not be based around these specific calls. Future areas of work, for example that current board members are interested in developing for EPPOSI focus on health data governance, and the challenges of chronic and rare diseases.

The EPPOSI team is looking forward to welcoming you to our meeting on the 9<sup>th</sup> December and working with you to help EPPOSI regain its place at the heart of patient centred health technologies in Europe.