

Patient Engagement Strategy for Innovative Medicines

Summary and conclusions Take home messages

28, April 2016

Brussels

Anders Olauson

EPF Honorary President

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

European Patients' Forum:

- Umbrella organisation
- Active since 2003
- 64 members



Our Mission!

“To ensure that the patient community drives health policies and programmes that are adapted for their final users, patients.”

To go back to the objectives of our workshop today

- To identify appropriate levels and mechanisms of involvement of patients and patient organisations in IMI and its projects;
- To discuss the strategy for optimisation and coordination of patient engagement practice in different projects and realization of the patient centric aspiration of the IMI Strategic Research Agenda;
- To identify possible topics for future IMI research projects on enabling patient involvement in medicines lifecycle, including collaboration opportunities with similar and complementary initiatives in various countries and regions.

- **BTCured** demonstrated that meaningful patient involvement in IMI projects is possible provided it is properly resourced and takes place right from the onset
- **U-BIOPRED** showed that a committed, engaged and well-coordinated set of patient representatives can bring significant benefits to research outcomes.
- ***Both examples show:***
- Patients clearly bring a strong added dimension to many aspects of research delivery, from setting the direction of the research topic through to the dissemination of outcomes, and we would strongly recommend other groups to take advantage of this essential perspective in their research.

- **Achieving meaningful patient involvement** which looked at ways to optimise and stimulate patient involvement, the necessary tools/resources, identify areas where patient involvement is lacking
- **Creating an appropriate framework, governing principles, coordination, and boundaries**
- **Addressing collaborative challenges, sensitivities, conflict of interest** (patients vs. industry/society/government, patient involvement on both development and approval sides, hurdles, barriers and boundaries).

- View from patients
- View from industry
- View from EMA



Some thoughts

- Mind set change – where is the true obstacle
- Advisory board with Patient representation for IMI
- Framework that works for all, and everywhere; that is to dance on all wedding, not only IMI
- Leadership in the various consortiums or projects.
- Sustainability on all levels, not only funding but also skills, who's responsibility? Need to continue to provide education and training to patients and patient organisations, but also operationalise patient engagement putting in place the right enabling infrastructure
- Project not only where Patient can/should be involved but also is the target. Need for a robust IMI patient engagement strategy to ensure that patient engagement is universally understood, recognised, and effectively upheld where it needs to be
- Pierre said; Why – How – What?
- We heard a lot now, and know a lot now, so time for action's

**THANK YOU ALL
ESPECIALLY TO
Pierre, Magda and all who
made this happend!!**