

Workshop

Patient Engagement Strategy for Innovative Medicines

27 - 28 April 2016 Crowne Plaza Brussels Airport Hotel

Da Vincilaan 4 • Brussels • Belgium

Workshop objectives

The overarching objective will be to assist IMI in further developing its patient engagement strategy and in particular to:

- identify appropriate levels and mechanisms of involvement of patients in IMI and its projects;
- 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;
- 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.

Wednesday 27 April 2016

19:30 – 22:00 Working dinner at Crowne Plaza Brussels Airport Hotel

All meeting attendees are invited to a networking dinner where we can get to know one another, as well as already start discussing interesting ideas around patient engagement in IMI and beyond.

We will start with welcome drinks at 19:30 followed by dinner at 20:00.

Thursday 28 April 2016

08:30 – 09:00 *Registration*

09:00 – 09:05 **A word of welcome**
Pierre Meulien, Executive Director, Innovative Medicines Initiative

09:05 – 10:20 **SESSION 1: Advancing patient engagement in IMI**

Chair of the session: Magda Gunn

Objective: to discuss meaningful patient engagement in IMI and beyond: who and how to involve, best practices, success factors, added value, challenges, and to explore existing gaps.

09:05 – 09:20 **Case study 1**
U-BIOPRED, David Supple (Asthma UK)

09:20 – 09:35 **Case study 2**
BTCure, Maarten de Wit (EULAR)

09:35 – 10:00 **Discussion**
All participants

10:00 – 10:20 *Coffee break*

10:20 – 12:00 **SESSION 2: Patient involvement in medicines lifecycle** **Break-out discussions**

Objectives: The session will be divided into 3 themes of patient involvement in medicines lifecycle. The workshop participants will be pre-assigned into the 3 different themes. Each group will have 1 h to discuss their topic. The discussion should lead to potential solutions /recommendations taking into account the perspectives from all stakeholders involved.

Theme 1 **Achieving meaningful patient involvement** (ways to optimise and stimulate patient involvement, necessary tools/resources, identify areas where patient involvement is lacking e.g. pricing and reimbursement)

Rapporteurs: Tony Hoos (Amgen) & Mathieu Boudes (Eurordis)

Theme 2 **Appropriate framework, governing principles, coordination, and boundaries** (do appropriate mechanisms and principles exist, what are the boundaries of patient involvement)

Rapporteurs: David Haerry (EUPATI) & Petra Wilson (consultant)

Theme 3 **Collaborative challenges, sensitivities, conflict of interest** (patients vs. industry/society/government, patient involvement on both development and approval sides, hurdles, barriers and boundaries)

Rapporteurs: Kim McCleary (Faster Cures) & Bettina Ryll (Melanoma Patient Network Europe)

11:30 – 12:00 **Report from breakout sessions**
Rapporteurs to summarise main points from break-out discussions, 10 min per theme

Moderator: Olivier Arnaud, JDRF

12:00 – 13:00 Lunch

13:00 – 14:50 **SESSION 3: Way forward**

Chair of the session: Pierre Meulien, IMI

Objectives: To agree on concrete actions towards IMI strategy on patient involvement at all levels, such as: governance, strategy and agenda setting; involvement in IMI projects; research topics aiming to implement patient involvement in medicines lifecycle; as well as need for coordination and harmonisation of those efforts.

13:00 – 13:30 **View from patients and others**

Jan Geissler, EUPATI
Yan Le Cam, EURORDIS

13:30– 13:45 **Views from industry**
Magda Chlebus, EFPIA

13:45 – 14:00 **View from EMA**
Isabelle Moulon, EMA

14:00 – 14:50 **Open-floor discussion:**
Mechanisms for continued patient centric approach in IMI

14:50 – 15:10 **Conclusions**

Anders Olauson, European Patients Forum

For social media please use: #imi & #patientsinvolved