

## EFPIA Patient Think Tank – Issue Summary June 2016

The EFPIA Patient Think Tank provides a forum for an open exchange of ideas, information and perspectives between patient organisations and industry on topical issues impacting on patients. Our aim is not to create common positions, but to ensure that the patient voice is heard in the development of EFPIA policy and practice and give industry members the opportunity to discuss aspects of medicines research and development with the patient organisation community.

### Policy Update

The PTT was updated about the draft council conclusions, the Dutch roundtable on pricing, moves on cross-border pricing cooperation and the new data protection legislation, including its impact on the healthcare sector. There was further focus on the implications for research and terms of access to data and re-use for secondary purposes. It was stressed that, given the sensitivity of healthcare data, a high-standards environment must be put in place and that any communications around the use of healthcare data must be well-managed.

### White Paper on Working Together

Discussion centred on developing resources on working together to support ethical, open and transparent collaboration to benefit patients and developing a document to address this. The PTT addressed taking an overall principles approach vs. an issue-by-issue approach focusing on different touch points in the relationship across the medicines life-cycle. The group also stressed the need for a clear explanation as to how the document fitted into the wider regulatory and legal frameworks governing relationships. It was agreed that, based on the structure, a working group would be established to develop a first draft, maintaining an equal balance of industry and POs.

### TTIP

The industry's perspective on TTIP was highlighted during the meeting. It was agreed that feedback on EFPIA resources on TTIP from the patient organisation members would be sought.

### IMI Patient Engagement

The PTT was updated on ongoing work in IMI on patient engagement throughout the medicine's value chain, with emphasis on recent examples, such as the EUPATI programme. The group discussed what could be covered by a new IMI initiative, with a particular focus on barriers/goals/questions that should be addressed. The group concluded that the operationalisation of patient engagement in the research process is important. There was a need to develop a

methodology for the systematic involvement of patients in medicines R&D, as well as an approach to managing conflicts of interest.

### Health Collaboration Summit

The PTT was informed of the working groups' thoughts on the draft agenda, with the PTT agreeing with the focus on outcomes and sustainability (day 1) and working together (day 2). Additional suggestions came in the form of: showcasing positive examples of member states in improving sustainability; launching an introductory session with public health representatives; and providing an interactive format. There was agreement to share with the group a summary of objectives and set up a new working group call to finalise the programme.