

## **EFPIA Patient Think Tank – Issue Summary December 2015**

**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.**

### **Relevant EFPIA policy processes and positions to include patient perspective through the PTT**

The overriding purpose of the PTT purpose is to provide patient perspectives on relevant issues, rather than to create joint positions with industry. Nevertheless, it is essential that the PTT does not work in isolation because if patient perspectives are not heard across relevant work-stream and working groups it renders this input irrelevant

During the ensuing discussion, it was also decided that the group and secretariat should take effective measures to boost communications around and raise the visibility of the PTT with a view to raising awareness about its purpose and activities within EFPIA and across member companies and associations. While it will be vital to investigate processes for engagement with relevant EFPIA working groups, it was agreed that the first step would be to write to, outlining the PTT work areas and describing how to access the patient perspective through the group.

### **Patient and industry respective views on emerging and on-going policy EU**

The Think Tank agreed that a horizon scanning session on EU healthcare and related policy issues should be added as a standing agenda item at future PTT meetings. The objective would be to identify and share perspectives on policy issues that impact on healthcare, research and industry - an example being the agenda for the Dutch Presidency of the Council. To carry this out effectively, it was decided that input was required from EFPIA's Government and European Affairs sections.

### **Support for integration of patients in the R&D process**

The group stressed the relevance and importance of patient integration in the research and development process, particularly with a view to engaging with IMI as Europe's partnership for health research. As a result, in 2016, the Think Tank will focus on securing a comprehensive overview of current IMI projects with patient involvement and will furthermore scrutinise horizon scanning of upcoming calls. There is a need to collate examples of best practice patient organisation engagement through IMI projects, the group agreed.

Equally important is the drive to review IMI guidelines on patient engagement and, on the basis of this examination, to make the appropriate recommendations for improvement.

### **Transparency**

The group has highlighted the continued importance of the transparency agenda, noting in particular the efforts surrounding the disclosure of payments to health professionals by EFPIA members, commencing in June 2016. The group acknowledged that disclosure of these payments might impact on patients and patient organisations. It therefore supported the idea of greater engagement with health professional bodies and congresses on this issue as well as the creation of materials on disclosure for patient organisations and patients.

The Think Tank furthermore confirmed its desire to be kept up to date with other transparency initiatives.

### **Building trust and acceptance in patient-industry dialogue and multi-stakeholder collaboration**

The importance of open, transparent and constructive dialogue between all organisations that research and develop new medicines and the representatives of those who take the medicines, came into focus during the discussions. The group agreed that efforts must be made to ensure that the operation of the PPT continues to serve as an example of best practice in industry/PO engagement, with a particular emphasis on the transparency of the engagement process. It became clear that deliverables highlighted in the Matrix 2016 remains critical to the development of best practice mechanisms, going forward.

PTT members also stressed that particular emphasis be given to exploring the development of industry/PO dialogue at national level, incorporating other stakeholder groups. The PTT steering group agreed to develop a process to identify areas for a national dialogue project starting with undertaking a survey of members.

### **Mapping pricing issues**

Presentations to the PTT were offered by Nick Meade (EGAN) and Andy Powrie-Smith, detailing top-line perspectives on price and related issues, including: confidentiality of net price, European and national competencies, standardisation of definitions, value assessments, negotiations, stakeholder reactions to pricing issues, re-purposing of medicines, value added services, pan-European relative efficacy assessment, campaigning on price, differential pricing, cross-border pricing initiatives, off label use, profit and outcomes driven, sustainable healthcare.

The aim of the discussion was to identify areas for deeper exploration. The group agreed that price transparency, confidentiality of net prices, understanding the process behind price-setting and reimbursement based on outcomes were areas for future discussion.

### **Health Collaboration Summit Review**

The Group heard that the Health Collaboration Summit attracted almost 200 participants, with some 100 from industry, 50 from patient organisations and the rest from academia and other stakeholders. Overall feedback on the event was very positive. Delegates considered its content relevant and interesting, backed by effective organisation and a satisfactory venue. There was discussion as to whether to format next year might be more interactive, with fewer speakers and more time for open discussion and breakout sessions.

### **Topics for Further Exploration**

Healthcare sustainability and the outcome agenda  
Patient Empowerment / Patient Access  
Pricing and Reimbursement  
MAPPs and Adaptive Pathways  
Pharmaceuticals in the environment  
Package Information Leaflets  
How to involve patients in metrics/ standards / measurements  
Healthcare sustainability and the outcomes agenda  
Pricing and Reimbursement

Full copies of EFPIA Patient Think Tank meeting reports are available from EFPIA, upon request:  
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