EFPIA Patient Think Tank – Issue Summary December 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 looked at pricing models, the UN High-Level Panel on Access to Medicines and the wider debate on on IP and access. It was also informed of conclusions of the 17 June 2017 Employment, Social Policy, Health and Consumer Affairs Council (EPSCO) Council and the Lisbon Roundtable of Health Ministers, attended by representatives from Cyprus, Sweden, the Netherlands, Portugal and Ireland on 7 December 2017.

There was an update on the incoming Maltese Presidency of the EU and an overview of the forthcoming OECD Ministerial Meetings. Finally Member States's Joint Initiatives, including voluntary cooperation at EU level were also discussed.

EPF has produced a "core principles" document on pricing and value for group circulation and there was emphasis on trying to engage with policy-makers at a high level.

Value of Health Data

The aim of the project is build understanding of the value of health data and increase understanding about data security. There was consensus that the research-related provisions of the data protection regulation were critical. It was noted that the overlapping relationships between organisations where data moves freely should be explained clearly.

Health Collaboration Summit

210 stakeholders attended the Health Collaboration Summit this year. There were 718 tweets using the #HCS2016 and EFPIA, the European Commission and EMA were among the top 10 mentions. While feedback was positive, there was recognition of the need to narrow down the discussion topic to achieve more concrete conclusion and recommendations. Breakout sessions were also in focus to get meaningful input from participants. A steering committee meeting was set for January to discuss the format and possible topics for the next summit.

Medicines Adaptive Pathways

The discussion focused on risk assessment in the context of MAPPs, noting that political criticism of MAPPs is that it promotes drug approval through the back door. Although exponents of the EMA led MAPPs approach argue the aim is to get effective medicines to patients faster and safer. Patients need a positive trade-off between benefit and risk and to be informed of the legal aspects through education.