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EFPIA Patient Think Tank – Issue Summary September 2014

EFPIA's Patient Think Tank serves as a forum for both EFPIA members and European patients' organisations to come together in an active forum to discuss how industry can best meet patient needs. Following each meeting, an issue summary is posted on the EFPIA website. Below is the issue summary of September 2014.

Future Development of the Patient Think Tank

In an environment with increasing need and interest to engage patients as important stakeholders in drug development, health care decision-making and policies that impact patients, the Think tank should help to define and guide the industry and patient group interactions and address these changes with those setting and interpreting regulations.

The natural space for the Think Tank is in catalysing debate around the issues that matter about the way we research, develop and use medicines and how to enhance patient engagement in those processes. An implicit part of this is to look at how we maintain standards in the industry-patient relationships at both EU and national level and how we maintain external confidence in our relationship at the same time as deepening interaction.

The EFPIA-PhRMA conference ("Healthcare Collaboration Summit") in October is the start of what should be a more visible way of working, which should include engaging with other stakeholders

A second strand of the discussion was about how the patient perspective is embedded in the industry's decision-making processes. There are a huge number of patient-relevant activities going on within companies, and a wealth of industry-relevant discussion taking place in the patient community. However, the channels through which issues are shared and discussed are relatively narrow. How can EFPIA facilitate better communication?

Patient Access to Medical & Scientific Congresses

Think Tank members had expressed a strong desire to discuss the issue of patient representative access to scientific congresses. The issue was also prominent at the July EUPATI workshop as a visible example of the barriers to equal treatment that are still experienced by patients. An important distinction is often important to establish that many of the 'patients' attending congresses are very often not patients, but rather well established and largely professional patient group representatives.

Industry funding to scientific congresses is strictly regulated under the national codes derived from the EFPIA Code. EU legislation provides the framing context for the EFPIA code. The societies themselves set the agenda for the congresses, within a financial framework in which industry support is the major element.

The right of patient organisation representatives to access congresses is a sensitive issue, but exclusion seems problematic in the light of the increasing level of general patient knowledge, specifically from the emergence of expert patients and patient advocates and , the role that patients can provide in commenting on the effectiveness of medicines and balancing industry views

A number of innovative solutions to access have been explored or discussed, including special patient spaces within the congress; innovative booth designs; scheduling patient

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events before or after the main congress; and utilising badges to identify different types of participants and thereby regulating interactions.

As further action, a working group will be set up to explore the feasibility of a best practice approach, and, if feasible, to progress this best practice approach. The group will include patient associations, congress organisers and representatives of the societies.

Transparency

The two core areas under active development are transparency of financial relationships with healthcare professionals and clinical trial data transparency.

EFPIA has now launched its pharma transparency platform - http://pharmadisclosure.eu/ The platform has been built on strong support from HCP's and is intended as a way of responding to the need to explain why the industry has certain relationships, while increasing the level of available information about those relationships.

Regarding clinical trial data transparency, there will be an event in November 2014 to give a progress update on the implementation of the EFPIA/PhRMA principles.

Other Topics Covered

- Patient organisation involvement in the upcoming EFPIA-PhRMA conference.
- EUPATI workshop on meaningful involvement of patients in medicines R&D.
- EGAN-Roche meeting on transparency.

Full copies of EFPIA Patient Think Tank meeting reports are available from EFPIA, upon request: communications@efpia.eu