

## 1<sup>st</sup> Patient Engagement Forum

*Co-organised by PARADIGM, PFMD and EUPATI*

*Short report*

*Brussels, April 10<sup>th</sup>, 2018*

**Welcoming Comments** The forum's opening comments were made by Nathalie Moll, EFPIA Director General, who espoused that PARADIGM is a pivotal part of the EFPIA strategy and promoted active involvement and collaboration. This was followed by a series of partners. Nicola Bedlington, EPF's Secretary General progressed discussions from the pre-forum session (see attachment x) on the need for synergies with other initiatives, such as Patient Focused Medicines Development (PFMD) and European Patients' Academy (EUPATI), and stressed that speed and sustainability were imperative. These sentiments were echoed by Mathew May, Programme Coordinator EUPATI. He promoted collaboration and linkage across initiatives. The need for flexibility was touted by Magda Chlebus, Director Science Policy at EFPIA, in order to react to the changing landscape, she further expressed that this objective mirrors PARADIGM's remit. While Nicholas Brooke, CEO of PFMD recounted that patient engagement is an investment and there is an interest to expand past the innovators and early adopters, such as those at the forum, to collaborate to become a majority.

**Overview of PARADIGM Stakeholder Voices** The different communities spoke of the need for conversion, to facilitate patient engagement becoming the norm, and some noted the requirement to demonstrate its added value. While different constituencies are represented, there is a shared focus on patient education and training, guidance on engagement, and ultimately sustainability. In the end, the ecosystem needs to be prepared, and fortification is derived from metrics. Metrics that are relevant to each of the stakeholders, who come to the process with often unique needs, is not an easy task. Co-creation is the pathway to sustainability, and finding synergies, while resisting competition is fundamental to success. PARADIGM provides a legitimate place where regulators and industry can meet, learn from one and other and share best practice. EMA and HTA bodies can facilitate the advancement of patient engagement to a new level. **Presenters:** *Walter Atzori (Alexion), Pietro Mario Erba (AIFA), Juan García (EMA), Virginie Hivert (EURORDIS), Paul Robinson (MSD), Tjerk Jan Schuitmaker (VU Amsterdam) and Daniel Schryver (JANSSEN).*

### Workshops Broaden Input across Stakeholders

- ***The Survey: Prioritization of Topics and Questions*** Key issues related to the survey including the need to narrow down the questions for each stakeholder group and determining how to accomplish translation was discussed and potential solutions identified.
- ***Building the PARADIGM Story*** An overview and discussion of the communications plan and the storytelling team (co-creation of the narrative around PARADIGM) was followed by breakout sessions that identified areas for operational excellence.
- ***Getting the Most of the Survey Which Stakeholders and What Methodologies*** An overview of some distinct considerations for people with cognitive impairment, rare diseases and children was presented. Input was gained on the best pathway to obtain appropriate industry responses for the survey.
- ***Assessing the Value of Patient Engagement*** A short questionnaire was employed, as well as discussion groups. The most feasible indicators for measuring patient engagement at three decision points were identified. Additionally, possible types of case studies were classified.

**Reflections on the Day** (Project Team composed of work package leaders and a representative from FSJD) 34 active partners joined forces to implement actions, recognizing the need to work with related patient initiatives. The forum was realistic and aspirational, allowing for practical patient engagement to happen - modeling the future.

## Pre-Forum Session on PFMD and EUPATI: Building on Initiatives to Advance Change

A pre-forum session was held to review the high level scope of PFMD and EUPATI. The palpable synergy with PARADIGM as well as these initiatives' complementary nature was highlighted. The presenters included Begonia Nafria Escalera, Jan Geissler, Tony Hoos, Roslyn Schneider, and Soren Eik Skovlund.

It was noted that PFMD provides tools for patient engagement across geographies and throughout the medicines lifecycle, and unlike PARADIGM is not limited to a specific timeframe. Capacity building of patient representatives is the tenor of EUPATI, enhancing their ability to be thought partners, as they actively engage in medicine development, its initial remit has centered in Europe.

The speakers were clear about PARADIGM's opportunity to build on the ongoing work of these projects, since it encompasses these topic areas and provides an opportunity for incremental advancement and change. Differences exist, PARADIGM is acutely focused on three points in the medicine lifecycle (research priorities, design of clinical trials, early dialogue with regulators and HTA bodies), and is 30 months in duration demanding laser focus.

It was apparent that the order of the day is iteration rather than duplication, PARADIGM is yet another stepping stone in the pathway to evolution of the ecosystem to imbed patient engagement as the rule, rather than the exception.

# 1<sup>st</sup> Patient Engagement Forum

## Agenda

9h00 – 10h30 PFMD, a collective effort to making patient engagement systematic

10h30 – 11h00 Coffee break

11h00 – 12h00 Welcome address / Why a common Forum? / General presentation / Why being involved

12h00 – 12h30 Q&A time

12h30 – 13h00 PARADIGM International Liaison Group

13h00 – 14h00 Lunch

14h00 – 15h15 Parallel workshops #1

- workshop A: The survey in PARADIGM: prioritization of the survey topics and questions
- workshop B: Building the PARADIGM Story

15h15 – 15h45 coffee break

15h45 – 17h00 Parallel workshops #2

- workshop C: Assessing the value of patient engagement
- workshop D: Getting the most of the survey - which stakeholders and what methodologies

17h00 – 17h30 Next 6 months of operations

# 1<sup>st</sup> Forum on Patient Engagement

## List of Participants

- Sheuli Porkess ABPI
- Harriet Adams ABPI
- Ana Diaz AE
- Dianne Gove AE
- Pietro Mario Erba AIFA
- Giorgia Viceconte AIFA
- Walter Atzori ALEXION
- Mats Ericson AMGEN
- Pooja Merchant BAYER
- Matthias Gottwald BAYER
- Wolf See BAYER
- Jackie Dudley COVANCE
- Maria Duterte EATG
- Giorgio Barbareschi EATG
- Emilie Fillod EFGCP
- Ingrid Klingmann EFGCP
- Magda Chlebus EFPIA
- Zsofia Bakonyi EFPIA
- Kirsty Reid EFPIA
- Nathalie Moll EFPIA
- Juan Garcia Burgos EMA
- Mathieu Boudes EPF
- Matthew May EPF
- Valentina Strammiello EPF
- Nicola Bedlington EPF
- Letizia Gambini EPF
- Anna Trzcinska EPF
- Zilvinas Gavenas EPF
- Sara Gayarre EPF
- Dominique Hamerlijnck EUPATI Alumni
- Viktoria Fonsou EUPATI Alumni
- Joan Jordan EUPATI Alumni
- Virginie Hivert EURORDIS
- Elisa Ferrer EURORDIS
- Begonya Nafria Escalera FSJD
- Joana Claverol Torres FSJD
- Lars Joens GRT
- Deborah Russell GRT
- Kay Warner GSK
- Pauline kitchiner GSK
- Sandra Garcia IACS
- Maria Jose Vicente-edo IACS
- Iwona Jabonska IMI
- Daniel De Schryver JANSSEN
- Robert Kroes LILLY
- Gianluca d'Anzeo LILLY
- Anders Blaedel Lassen LUNDBECK
- Paul Robinson MSD
- Rob Lopata MSD
- Laura McKeaveney NOVARTIS
- Emilie Voltz NOVARTIS
- Lasse Funch Jacobsen NOVO NORDISK
- Paula DeCola PFIZER
- Roslyn Schneider PFIZER
- Jan Geissler PFMD
- Helena Harnik PFMD
- Søren Eik Skovlund PFMD
- Danielle Barron PFMD
- Tony Hoos PFMD
- Roxana Radu PFMD
- Diane Driver PILG representing Transcelerate
- Christina Åkerman PILG representing ICHOM
- Birka Lehmann PILG as external expert
- Inka Heikkinen PILG representing DIA
- Daniel O'Connor PILG representing MHRA
- Julia Chamova PILG representing ISPOR
- Jürgen Kübler PILG representing the IMI project PREFER
- Isabelle Huys PILG representing the IMI project PREFER
- Violeta Stoyanova PILG as external expert
- Rebecca Vermeulen ROCHE
- Vinciane Pirard SANOFI
- Mathieu Jouannin SANOFI
- Juliette Maillet SERVIER
- Anne-Claire Julienne SERVIER
- Eva Molero SYNAPSE
- Luca Bertoglio SYNAPSE
- Nicholas Brooke SYNERGIST
- Chi Pakarinen SYNERGIST
- Daphnee Pushparajah UCB
- Laurence Leonardy UCB
- Nicholas Fahy University of Oxford
- Suzanne li University of Oxford
- Barbara Haake VFA
- Tjerk Schuitmaker VU-ATHENA
- Nicole Goedhart VU-ATHENA