



European Alliance for Personalised Medicine

EAPM Bulletin: Issue 16, July 2016

www.euapm.eu

Brexit will not stop Alliance's work

Welcome to the July newsletter.

As Europe (and around half of the UK) reels in the aftermath of the referendum on Brexit, EAPM will be watching closely as events unfold.

Nobody knows exactly what will happen yet, but the Alliance will continue to engage with its stakeholders and experts in the UK.

Health is a national competence across the EU, of course, although centralised legislation such as rules on IVDs, data protection, clinical trials and cross-border health care have all been designed to apply across the 28 Member States.

It is clear that there is already a huge need for better collaboration across medical disciplines and borders, therefore Brexit will not help anyone in that regard.

On a legislative note, the new Clinical Trials Regulation, for example, seeks to turn current outmoded trial models into those fit-for-purpose in a health environment that has seen the rapid emergence of personalised medicine.

It will introduce an EU-wide data base and much greater collaboration and harmony - all for the benefit of research and, thus, eventually patients. It will also reduce red tape and simplify the 'bench to bedside' process in many cases of innovative drugs and treatments, usually when the medical product in question carries less risk.

If the UK steps back from that and other legislation, it will face extra administration problems when holding trials in EU countries.

Among other issues, post-Brexit, the UK will possibly have access to smaller data sets than those in the Union. Not only that, but the EU may lose data from the UK. This effectively means less collaboration and sharing of information - a scenario that will affect patients, be less efficient and more expensive.

It's all rather regrettable from the broader point of view but the Alliance will continue to work in whatever relevant areas it can.

Summer School for HCPs

Coming up fast (3-7 July) is EAPM's first Summer School for young healthcare professionals. Entitled *'TEACH' (Training and Education for Advanced Clinicians and HCPs)*, the school will be held at Cascais, near Lisbon, Portugal.

In the pipeline

- **3-7 July: Summer School for HCPs, Cascais, Portugal**
- **12 July: Internal meeting on development pathways for personalised medicine**
- **13 July: Internal meeting on translational research**

It is primarily aimed at young healthcare professionals aged 28-40, but with patient involvement, also.

In 2014, a key meeting was held between medical societies and EAPM in Brussels. There, it was determined through consensus that a multi-stakeholder approach to HCP training was urgently required.

The concept was developed and noted in Luxembourg's landmark Council Conclusions on personalised medicine.

Meanwhile, EAPM's HCP training strategy has been presented to the European Council, MEPs and the Commission.

Following the Summer School, quarterly webcasts will be held to update HCPs regarding developments to further aid communication with patients.

Over the course of the school, a faculty of experts will oversee plenaries, group discussions and interactive role play sessions involving those HCPs enrolled on the course. View the programme here.

Into the future with the Alliance

EAPM will be moving forward during the second half of 2016 and also has much planned for 2017, including its annual conference (in association with the Maltese Presidency of the EU) and continuing work in the regulatory area.

The SMART Outreach programme will also be stepped up across Europe.



SMART

Smaller Member States And Regions Together

Highlights include:

- September-October 2016: Outreach in Germany, Spain, Portugal, Italy, Poland, Bulgaria and Ireland plus EHFG
- November-December 2016: Outreach meetings in Italy, Germany and Portugal, plus Summer School webinar
- January-May 2017: Meetings in Spain, Romania, Germany and Italy, EAPM Annual conference, Outreach in Ireland and Portugal, plus Translational Research
- June-November 2017: Outreach events in Ireland, Italy, Spain, Portugal and Germany plus ESMO Congress, Madrid, and first EAPM Congress, Belfast

The Working Groups, secretariat and members spent much of June on this forward planning and more details are available in EAPM's 'review and initiatives' document, which will be circulated in the next week.

EHA in Denmark

Recently, EAPM went to Denmark for a meeting as part of the European Hematology Association congress.

This was entitled: '*Crossing the Rubicon from Copenhagen – EHA leading the way*'.

The event included topics such as *Driving innovation forward: The patient perspective; Providing further evidence for the benefit delivered by PM to health systems, and; Supporting health economics research of PM to support decision-makers.*

HARMONY

A project called 'HARMONY' has been submitted by EAPM and the Alliance awaits final confirmation in mid-to-late July.

The proposed project will bring together leaders in the field to build up a network of excellence that integrates big data from high-quality multi-disciplinary sources and will take a lead in advancing progress in various areas of hematologic malignancies.

HARMONY will allow a more rapid detection of promising treatment strategies, adverse events and impact on outcomes, taking current demographic changes as well as individual patients' wishes into account.

Special issue on Access

EAPM has published a special issue on *Access for All: A Personalised Approach*.

This is a *Public Health Genomics* special issue on challenges and opportunities for enhanced patient access to personalised medicine in Europe, and is available online now, here.

Co-written by Alliance members, the publication takes into account the Luxembourg EU Presidency issuing its Conclusions on personalised medicine at the end of 2015, highlighting how "the development of personalised medicine may offer new opportunities for the treatment of patients in the European Union...allowing healthcare providers to offer better-targeted treatment, avoid medical errors and reduce adverse reactions to medicinal products."

Matters such as increasing costs, inequitable access across



European countries and regions and the need for an ethical, regulatory and reimbursement environment are currently undermining the integration of personalised medicine at European and national levels.

Recognising the need to address these important issues, EAPM assembled a multi-stakeholder panel to identify and precisely define the critical barriers that limit personalised medicine uptake, while also developing putative solutions that will enhance patient access across Europe.

The outputs from their discussions are captured through a series of articles, complementing the activities of the EAPM's Working Group on Access, which is surveying the European landscape and developing policy recommendations in this complex domain. Click [here](#) to access the document.

Groundbreaking congress in Belfast

Forward As One: 'Making personalised medicine a reality at national level'

First EU Member States' Congress on Personalised Medicine Belfast, Autumn 2017

After four annual high-level Presidency conferences held in Dublin and Brussels, EAPM plans to organise a congress in Belfast next year, running over three days.

The Alliance believes that the time has come to find practical on-the-ground ways to turn the dream of personalised medicine into reality.

This essentially means the practical integration of personalised medicine into Member State health care systems as swiftly and efficiently as possible.

There are many problems that require solving, quickly, if we are to see the right treatment for the right patient at the right time for every one of the EU's 500 million citizens regardless of where they live and their financial status.

Structure of the Congress

Each day will begin with a three-hour plenary session on a particular topic or topics. After lunch, each afternoon, the congress will break into various symposia which will act as think-tanks, with a last 90-minute plenary in the main hall during which selected think-tanks will report briefly and a Q & A will ensue. Topics for the think-tanks are expected to include:

- Making the most of the success of IMI and IMI 2
- Integrating new models for clinical trials
- Introducing consensus-based standards in vital areas, agreed nationally for pan-EU use
- Big data and supercomputing, and bringing about cross-border sharing
- MAPPs and HTA bodies (speeding up bench-to-bedside)
- Education of healthcare professionals at national and pan-EU level

Belfast, where the Alliance's 2017 Congress will be held



As well as the think-tanks that will be part of the programme proper, organisations will be invited to hold their own side meetings/roundtables and industry sponsored sessions in dedicated rooms.

An exhibition hall will also be on site with a view to showcasing the latest developments in technology that are being brought to the personalised medicine arena.

In the news

As ever, EAPM has had articles published in the media recently. Readers can access these by clicking on the titles below.

[#Health: Patient safety is a pan-EU issue](#)

[#EAPM: Oncology conference backs patient-centric treatment](#)

[#EAPM heads to Romania for personalised medicine Outreach programme](#)

[#EAPM: Copenhagen congress finds personalised medicine is in the blood](#)

[#Health: Publication of EAPM Special Issue on 'Access for All: A Personalised Approach'](#)

[#PerMed2016: Commission conference pushes personalised medicine agenda](#)

Follow EAPM on Twitter [@euapmbrussels](#)



About EAPM

The European Alliance for Personalised Medicine (EAPM) , launched in March 2012, brings together European healthcare experts and patient advocates involved with major chronic diseases. The aim is to improve patient care by accelerating the development, delivery and uptake of personalised medicine and diagnostics, through consensus.

As the European discussion on personalised medicine gathers pace. EAPM is a response to the need for wider understanding of priorities and a more integrated approach among distinct lay and professional stakeholders.

The mix of EAPM members provides extensive scientific, clinical, caring and training expertise in personalised medicine and diagnostics, across patient groups, academia, health professionals and industry. Relevant departments of the European Commission have observer status, as does the EMA. EAPM is funded by its members.

**Contact: Denis Horgan
EAPM Executive Director
Avenue de l'Armee/Legerlaan 10, 1040 Brussels
Tel: + 32 4725 35 104
Website: www.euapm.eu**