



# European Alliance for Personalised Medicine

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## EAPM: Key Madrid event plus Belfast Congress

Welcome to EAPM's September newsletter. The Alliance hopes that all of you managed to take some time off during the summer, and here we are back again with much to do.

Coming up very quickly is a key meeting. This is an EAPM/ESMO roundtable on 10 September in Madrid. The meeting at the ESMO Congress in the Spanish capital will be the fifth such roundtable conducted by the Alliance.

This interaction is one key aspect of EAPM's stated goals - to engage with the medical community whenever possible, and at every level.

The prestigious annual ESMO Congress will host a roundtable on 'Personalised Medicine: Translational Continuing Education Initiative', organised by the Alliance.

The meeting will take into account the fact that new discoveries - generated from a deeper understanding of the human genome - are driving a paradigm shift in medicine from a one-size-fits-all approach to one which is personalised and targeted to the individual.

This shift is rapidly progressing in oncology but is slower in other areas. And, while there are many barriers to innovation in clinical practice - including market access, scientific, and/or regulatory challenges - the biggest challenge across the healthcare system is continuing medical education.

Education should be a top priority when it comes to modernising healthcare systems, yet most educational programmes are less than optimal (an area that EAPM has already begun to address through its Summer Schools held in 2016 and earlier this year).

To solve this educational gap, the Alliance proposes a multi-phase project to develop market-specific and disease-area educational pilots that can be eventually scaled up to offer broad educational programmes.

Renowned oncologist and EAPM co-chair Gordon McVie, as well as the Alliance's executive director Denis Horgan, will get the roundtable underway, setting out the framework before a question and answer session.

### The Alliance and consultations

EAPM is continuing to focus on work aimed towards integrating innovation into EU healthcare systems.

### In the pipeline

- 12 Sept: ESMO/EAPM roundtable, Madrid
- Various dates in September: WG Meetings
- 12 Oct: World Sight Day, European Parliament, Brussels
- 26-27 October Balkan PM conference
- 27-30 Nov: EAPM Congress, Belfast
- Open now: Session Calls for Congress

These include *Transformation of Health and Care in the Digital Single Market*, explained later in this section, (see [link](#)), as well as a document on *Developing National eHealth Interoperability Standards for Ireland* which you can read [here](#). Also, we are consulting on an Irish Department of Health paper on biosimilars, available by clicking this [link](#).

The *Transformation of Health and Care in the Digital Single Market* mentioned earlier dovetails well with the MEGA proposal (Million European Genomics Alliance) that EAPM had previously put forward [here](#).

Generally speaking, the Commission wants to develop a European health record format that citizens can access from anywhere in the EU. The EU Executive is outlining its plan for a communication on digital transformation in health and care which is expected by the end of the year.

The communication, which was already announced as part of the Digital Single Market midterm review, is the latest attempt by the Commission to push countries to make patient care across the EU more seamless. A further goal is to "advance research, disease prevention and personalised health and care in key areas by enabling access to data sets and medical expertise across borders".

It will set out how different EU funding programmes can be used to support the "large-scale implementation of interoperable digital services that support health system reforms and capacity-building towards more patient-centered



and integrated care". This topic will be among many to be discussed at the EAPM Congress (see later in this letter).

### Preventable blindness White Paper

A White Paper championing preventative measures to fight blindness will be launched in the Brussels European Parliament to coincide with World Sight Day 2017.

The White Paper has been written by the European Forum Against Blindness (EFAB), and its associate organisations, including EAPM.

This year, World Sight Day will take place on 12 October, under the banner 'Make Vision Count'. It is an annual day of awareness to focus global attention on blindness, visual impairment and rehabilitation of the visually impaired, and was first held in 1998.

Key decision makers, policymakers, government officials, patients, partners/donors and the wider health community participate in World Sight Day, with annual events taking place all over the globe.

The White Paper will highlight that eye disease and its prevention is a major issue in Europe today and will only become bigger as the 500-million-plus population ages (and the incidence of, for example, diabetes grows).

To support a common effort on behalf of all stakeholders in this area, the White Paper, agreed by consensus, will explain the need for, among other things, a more preventative approach to blindness across the EU's Member States.

There are some 39 million blind people in the world, but 80 per cent of blindness can be cured or prevented.

That's 31.2 million people who are blind when they needn't be.

And studies suggest that eye disease costs society in Europe some €20 billion, causing a significant economic burden.

Much of these costs are due to day-to-day care for the blind by relatives and friends. This, therefore, has an impact on society as a whole, not just on the sufferer.

Debilitating sight loss can result from such conditions as cataracts (by far the most common reason), diabetic retinopathy, glaucoma and wet AMD, among others.

EFAB and its associates strongly believe that the EU should be doing more to facilitate research and raise awareness of eye diseases, which have a low profile compared to other diseases that adversely affect the quality of life, on a daily and long-term basis, of sufferers and have a huge impact societally and financially. Currently, there is far too little awareness to push Europe into tackling this at policy level.

EAPM is happy to be party to this White Paper as we hope that the Commission, and all Member States, will pull together to fight blindness by early diagnosis. Prevention is the answer.

### Access and the WHO

Access to medicines is sure to be a priority at the World Health Organization throughout 2018.

Unfortunately, supporters of a UN report on drug prices and intellectual property feel that recently departed Director General Margaret Chan (she was replaced on 1 July) ignored a push to make the report a stand-alone item in WHO discussions.

This is an issue that EAPM's Working Group on Access and Value will be following on a regular basis.

### Estonia and health

EAPM is working closely with the Estonian Presidency of the EU during its six-month spell at the helm.

Earlier, in July, the European Parliament's Committee for Environment, Public Health and Food Safety heard messages from Jevgeni Ossinovsk, Estonia's Minister of Health and Labour.

Among other things, Ossinovsk said that within the framework of the Digital Single Market, Estonia would like to promote cooperation and coordination on eHealth cross-border matters, in order to create the necessary preconditions for wider use and cross-border movement of health data.

The minister emphasised the need to bring together the EU's



citizens, adding that health is one of the areas that concerns all of us. Being able to live a healthy, active, and fulfilling life also contributes to the economy, he said.

Ossinovsk pointed out that European cooperation can bring substantial added value by tackling common health challenges. The main disease burden comes from chronic diseases, namely related to lifestyle, he added. Diseases, he said, do not respect borders, so concerns can often be shared.

Under the Presidency, Estonia plans to continue pushing the EU health agenda by focusing on, for one aspect, advancing digital innovation in health. Free movement of data is one of the overall priorities of the Estonian Presidency, as it also is for EAPM.

Member States are facing common challenges in sustainability of their health systems, Ossinovsk said, and digital technology and innovation can support the overall goal of the policy. People would be healthier and the system would be more sustainable.

For patients, digital solutions offer easy and secure access to information and the possibility of better understanding and management of their health. This is particularly important for people who have chronic conditions.

Patients would benefit, but the data could also be used for research and innovation. But Europe needs to be smart in the way in which it uses data. It should be possible to use data in a secure individual and collective manner, Ossinovsk explained.

This would protect the privacy of patients, but also give access to data that would not hamper research.

Building on the opportunities of the Digital Single Market, Europe should create favourable conditions for innovative digital solutions to be scalable, by promoting the use of European and international standards

Also, the Commission's mid-term review of the Digital Single Market has brought digital transformation to the fore.

This will be discussed in Tallinn on October 16-18, where policy makers and stakeholders will gather to learn about recent policies and technological development. These stakeholders will

also be part of discussions to shape a roadmap of actions. They are expected to adopt Council Conclusions on this matter in December.

At the meeting, Ossinovsk said that too little is happening in the health area and what should be happening is not.

On data protection and digital health, he said that these are the major arguments used against innovation. In this regard, the EU co-legislators have adopted several reports and legal acts on data. Now they have to continue improving this, he said.

## Belfast Congress

EAPM is now focusing hard on the First Annual European Personalised Medicine Congress, to be held across four days (27-30 November) in Belfast, Northern Ireland.

At the time of this newsletter, 85% of speakers have been confirmed and a substantial number of scientific abstracts have now been received. Meanwhile, EAPM has decided to extend the **early bird registration** to 22 September. Here's the [link](#) and we advise interested parties to sign up as soon as possible.

The Congress website, the abstracts portal, and online [registration](#) have been launched and the current programme is available to view [here](#)

Key areas that the Congress will focus on include:

- **Patients**

Modern-day patients are better informed than ever before and are demanding to share in co-decision-making about issues affecting their treatments. They are also hugely in favour of being able to share their own private health data (under strict ethical and privacy provisions) for the benefit of fellow patients and future generations.

- **Education & Training**

Healthcare professionals (HCPs) are falling behind with front-line



knowledge as developments in personalised medicine move swiftly. Europe must put programmes in place to bring, and keep, these HCPs up to speed.

#### • **Regulation**

Proponents of personalised medicine believe that much legislation governing aspects of healthcare is out-of-date and not fit for purpose in these fast-changing times.

Regulations and directives must be brought up to modern levels through a consensus of experts and key actors, including patients.

#### • **Research & Development**

EAPM has always promoted state-of-the-art research, and this will be a focus of the Belfast Congress which will be held at The Waterfront venue (pictured above).

### **Useful Congress links**

[Congress Programme](#)

[About the Congress](#)

[Session formats](#)

[Sessions styles](#)

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### **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.**

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