



European Alliance for Personalised Medicine

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Politics aside, it's time for patients to benefit

Welcome to our May newsletter. Election season is upon us in two major European countries, France and the UK, with any populist, post-Brexit reactions in Paris and beyond proving a concern to those who cherish the EU project.

We will soon know who will replace outgoing President François Hollande in the Elysée Palace - the far-right's Marine Le Pen or her pro-EU rival Emmanuel Macron.

The Alliance, as ever, is calling for the speedier and smarter integration of innovation into healthcare systems. There is currently a lack of incentives in this regard and what is needed from our political leaders - whoever they may be - is actual implementation rather than simply political blah-blah.

Of course, the Alliance recently held a highly successful [fifth annual conference](#) at the prestigious Bibliothèque Solvay.

Sponsored by Siemens, Intel, Novartis, Medtronic and MSD Be well, and entitled *'Innovation, Guidelines and Screening: The Case of Lung Cancer'*, the conference produced a core working group set up to develop the issues arising on the day.

This is in order to drive forward and implement the outcomes into policy recommendations at EU, national and local level.

To support this common effort, a White Paper will be published in the coming months in concert with a consensus document setting out the mechanisms and rationale for implementation.

Support for European Reference Networks

European Reference Networks (ERNs) are virtual networks involving healthcare providers across Europe. They aim to tackle complex or rare diseases and conditions.

EAPM, together with members the European Society of Medical Oncology, European Respiratory Society, European Haematology Association and European Association of Urology, has worked hard to drive the agenda.

The Alliance's work with various ERNs has included those on respiratory diseases, adult cancers, haematological diseases, as well as urogenital diseases and conditions. It will continue.

Letter from MEPs to the Commission

A communication, drafted by the Alliance and signed by MEPs, will go to the European Commission as part of a call for a Data

In the pipeline

- **10 May: Access Working Group meeting**
- **16-17 May: International Forum on Cancer Patients Empowerment, Milan, Italy**
- **23 May: Regulatory WG meeting, Brussels**
- **22-25 June: EHA Congress, Madrid, Spain**
- **27-30 June: Summer School, Bucharest**
- **10 Sept: ESMO/EAPM roundtable, Madrid**
- **27-30 November: EAPM Congress, Belfast**

Task Force to develop further the EU executive's digital strategy in health, and a one-million-genomes initiative for Europe.

The two initiatives, say the MEPs, are necessary to further the cause of personalised, targeted medicine. Among other points, the letter states: "With rising healthcare costs and individual health systems being increasingly challenged, genomics has the potential to impact the health of all of us and provide diagnostic, economic and efficiency benefits, ensuring that patients receive the right information and the right treatment at the right time.

"This will ease the burden on healthcare systems and lead to a healthier and, thus, wealthier, Europe."

Milan (and more) in May

Coming up this month are three meetings, beginning on 10 May with the gathering of EAPM's Access Working Group, as well as a further working group meeting - this time on regulatory affairs - which will take place on 23 May.

In-between, EAPM will be present for the *International Forum on Cancer Patients Empowerment*, in Milan, from 16-17 of May. The keystone is to align efforts internationally via a central focus to coordinate this effort.



The event is being organised by the Università degli Studi di Milano, in cooperation with the Fondazioni Umberto Veronesi. The founder of the latter, Umberto Veronesi, died at the age of 90 and was a leading light in fighting and preventing the terrible disease of breast cancer, as well as an activist in anti-tobacco campaigns.

Next to EAPM, other leading organisations joining the Forum include the European Cancer Patient Coalition, the European Society of Medical Oncology, and the European Organisation for the Research and Treatment of Cancer.

Delegates at the Forum will publish a Call to Action.

This Call to Action will remind the EU and its Member States of the EPAAC and CanCon initiatives and call on the EU and those Member States to collaborate.

CanCon followed in the wake of EPAAC. It is led mainly by Member States with the support of the EU, and also involves other stakeholders, including NGOs working across Europe.

CanCon has the goal of reducing cancer incidence by 15% by 2020 and the Call to Action urges those Member States that have signed up to various objectives to waste no time in implementing the recommendations as agreed.

The Alliance hopes to launch a White Paper on patient empowerment during the Milan forum.

Further action for 2017

EAPM is engaged in strengthening EU cooperation on Health Technology Assessment (HTA) and was part of a recent Commission consultation on the subject.

The consultation closed earlier this year, but the topic represents a core issue that the Alliance is following up with the institutions.

Meanwhile, a mid-term briefing for MEPs will be launched and distributed by the Alliance in May.

This will concentrate on several areas:

- ***What value do we put on health?***
- ***Personalised medicine and the European Parliament***
- ***Changing times in healthcare***
- ***Aligning laws for personalised medicine***
- ***Priorities for the European Commission***
- ***Patient power on the rise***
- ***Managing expectations***
- ***The role of carers***
- ***Prevention measures***

Incentives in healthcare

Aside from this, in June, EAPM will hold a meeting with the European Parliament to highlight the role of incentives in healthcare, bearing in mind the recent parliamentary report on improving access to medicines.

'Where is the value?' is a big question in many areas of life. One could argue that the current wave of Euroscepticism (most recently having been seen in the UK, and now France) is at least partly due to a perception that the European Union is not offering enough value to many of its citizens.

Added to this, while most people accept that innovation is good for citizenry, many question the perceived high prices charged by pharmaceutical companies for certain medicines - prices that many Member State healthcare systems have to forego.

The knock-on effect, of course, is that many patients are denied novel drugs and/or treatments, leading to a lower quality of life and sometimes avoidable death.



This will be a key topic of the Belfast Congress which will have the intention of coming up with concrete recommendations about how Europe can integrate all the new science into healthcare systems, with the goal of allowing citizens' access to all preventative and personalised care.

When it comes to value, such a situation would boost the standing of the EU, pharmaceutical companies and the medical arena as a whole.

Overall, of course, EAPM will continue to engage with MEPs to ensure their awareness of personalised medicine issues.

Meanwhile, we will keep a running dialogue with the Commission and Member States as part of our ongoing SMART Outreach programme.

TEACH Second EAPM Summer School

Following on from last year's success, a second Summer School for healthcare professionals will be taken east to Bucharest, Romania, and run from 27-30 June.

As it was in 2016, the school will be entitled 'TEACH', which stands for Training and Education for Advanced Clinicians and HCPs, and the goal is to bring young, front-line professionals up-to-speed with fast-moving developments in the field.

Aimed at age-range 28-40, TEACH holds to the thesis that equal access to high-quality healthcare must be made available to many more citizens than is currently the case.

Belfast Congress

During the coming months, EAPM will be focusing on and developing the policy asks that will be set out in this First Annual European Personalised Medicine Congress, to be held across four days (27-30 November) in Belfast, Northern Ireland.

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, while improving their interaction skills with patients.

- **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. Despite health largely remaining a Member State competence, regulations and directives must be brought 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. The Alliance's stakeholders have engaged often with IMI and the European Commission (for example, Horizon 2020) to discuss incentives for industry, patients and academics in the area of research and development.

The Congress, to be held at The Waterfront venue (pictured above), will see 35 parallel sessions plus ten presidential sessions during the week.

Here is a further link that readers should be aware of: to submit abstracts, click [here](#)

In the news

As ever, EAPM has been busy in the media. Click the link below to read one of our more recent articles.

[Looking for incentives in health care to boost the concept of 'value'](#)

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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.

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