



European Alliance for Personalised Medicine

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EAPM has a busy June, with more to follow...

Welcome to EAPM's July newsletter.

June was a pretty big month all around, with the Brexit talks finally getting under way with all they imply for the future of healthcare, not only in the UK, but across the EU as a whole.

For the Alliance's part, it was certainly busy: The end of June saw our second Summer School for young healthcare professionals, or HCPs, entitled '*New Horizons in Personalised Medicine*'.

This year, the concept was taken east to Bucharest, Romania, with the school taking place from 27-30 June. It followed on from last year's successful inaugural school held in Portugal.

Once again, the school had the name 'TEACH', which stands for Training and Education for Advanced Clinicians and HCPs, with the goal being to bring young, front-line professionals up-to-speed with fast-moving developments in the field.

Marius Geantă, President of the Center for Innovation in Medicine, said of the event: "Medicine is changing every second and HCPs have to keep on the right track in order to deliver the best care for patients."

Geantă added: "The TEACH Summer School for personalised medicine is the first, and remains the only, comprehensive educational programme for HCPs and we were honoured to host the 2017 edition in Bucharest."

EAPM's co-chair David Byrne, a former European Commissioner for Health and Consumer Affairs, said: "The title of the event was '*New Horizons in Personalised Medicine*', so among other aspects, the Summer School provided a forum for sharing ideas for innovation, and practicing communication skills."

"It allowed young HCPs to enhance their knowledge of personalised medicine and its potential, as well letting them offer feedback about the priorities they felt we should be zooming in on down the line."

And the Alliance's executive director Denis Horgan said: "In the changing world of healthcare in Europe, which of course includes the exciting new developments in personalised medicine, the ongoing education of healthcare professionals has, so far, been under-emphasised."

Horgan added: "I am delighted to say that 90 HCPs joined us in the capital of Romania, and that's an increase of around 30% on

In the pipeline

- **10 Sept: ESMO/EAPM roundtable, Madrid**
- **12 Sept: ERS/EAPM roundtable, Milan**
- **27-30 November: EAPM Congress, Belfast**

the first event last year. We're clearly going in the right direction, but much remains to be done."

Aimed at age-range 28-40, TEACH holds to the thesis that, if personalised medicine is to be in line with the EU and Member State principle of universal and equal access to high-quality healthcare, then clearly it must be made available to many more citizens than is currently the case.

With Brexit looming large, EAPM believes it is more important than ever to bring Europe together in a way that improves the already significant skills that HCPs possess to enable co-decision making which will effectively empower the patient.

'SMART Outreach' forum in Bucharest

Alongside the Summer School, EAPM held a forum in Bucharest. At the meeting, Romania's state secretary at the ministry of health, Corina Pop, identified specific issues facing Romania, saying: "We need to develop a National Cancer Plan which will include personalised medicine principles mandatorily, from screening to treatment."

She added: "We also need to see the establishment of a National Cancer Registry and other IT infrastructures aiming to develop an integrated 'Big' and 'Smart' data system."

"We also need to define fast tracks of evaluation and reimbursement for immunotherapies, personalised drugs and genetic testing, which demonstrate their value in clinical trials and are recognised as such by the European Medicines Agency."

Former European Commissioner for Health and Consumer Affairs David Byrne, who is also co-chair of EAPM, said: "Romania, like all EU countries has huge healthcare challenges as populations age and co-morbidities increase."

"Among the recommendations emerging today for



Romania are the establishment of a fund for access to innovation which can cover the costs of new immuno-oncological therapies, and the development of a national network of excellence centres in precision medicine, with accurate diagnosis capabilities.”

Marius Geanta, the president of the Centre for Innovation in Medicine, said that he was delighted that SMART Outreach forum was being held in Bucharest.

Geanta emphasised the need for: “the inclusion of predictive genetic testing in other national programmes, such as cardiology”, as well as “the inclusion of personalised medicine methods among the quality criteria in the accreditation of hospitals”.

The Alliance’s executive director Denis Horgan, meanwhile, said: “Romania, along with other EU countries, needs to work towards a definition of legislation in matters of compassionate use and other mechanisms of early access, which could help with access, including to immunotherapies.”

Horgan added that what is also necessary is the development of infrastructure for clinical studies in order to facilitate early access of patients, including to immuno-oncological medicinal products.”

Access to medicines

The European Hematology Association (EHA) held its 22nd annual congress late last month, and EAPM held a satellite roundtable meeting on Thursday 22 June.

It took place in the Spanish capital of Madrid, as part of a prestigious Congress that attracted some 15,000 delegates and speakers.

EAPM held its third event at the Congress, entitled ‘EU options for improving access to medicines.’

The Alliance’s Working Group on Access has been regularly discussing issues such as the EU’s problem over inequitable access, as well as the need for incentives and what exactly constitutes ‘value’ in this field.

With Brexit talks having just begun, and direct European

Parliamentary elections due in just two years, EAPM argues that, in the realm of healthcare, Member States need ‘more Europe, not less’. It is true, however, that achieving this ideal is made more difficult by the fact that health is a Member State competence and cooperation between the current 28 countries is sub-optimal.

It certainly won’t be helped by the UK leaving the bloc, (probably) in less than two years.

But Europe’s healthcare stakeholders remain busy and, in the wake of a European Parliament report on the topic of improving access, the meeting in Madrid elicited responses from the healthcare community regarding the way they envisage moving forward.

Ireland to join BENELUXA group?

When it comes to some kinds of inter-Member State cooperation and coordination in the realm of healthcare, readers will know that one example set up in 2015 led to the negotiations carried out by the Netherlands, Belgium, Luxembourg and Austria, operating as a single group, with drugs companies to guarantee, among other things, affordable prices for medicines for rare diseases.

Now a fifth Member State, Ireland, is considering whether to join the so-called BENELUXA group, according to Irish Health Minister Simon Harris. Ireland will make the decision in the coming weeks.

Dublin’s health minister has already signed an agreement with seven other Member States - these being Cyprus, Greece, Italy, Malta, Portugal, Romania and Spain - with the goal of finding ways and means, cooperatively, to improve access to medicines alongside other health technologies. This is known as the Valletta Declaration. There is no problem being in both groups, according to Harris.

Harris was quoted as saying that: “As these groups begin their work, at some point they will all have to be brought together... If you have three groups, for example, and they all think that joint horizon scanning makes sense, let’s do it.”

A meeting of the eight took place in Cyprus on 29 June, and



Harris added that he would like to see these Member States share drug price information. But there is a need, he said, to see “how we could do that in accordance with commercial law”.

The Alliance’s co-chair, Gordon McVie, said: “Our ageing population needs plenty of healthcare right now, and will need even more in the future as patients suffer from co-morbidities, yet healthcare systems acting alone are often failing to deliver.”

“The prices of medicines for rare cancer sufferers, for example, are sky-high. Meanwhile, bench-to-beside timelines for new drugs need to come down significantly without letting safety suffer.

“Cooperation between as many Member States as possible, and hopefully all of them, is certainly required, now and going forward,” McVie added.

Bidding continues to host EMA post-Brexit

The European Commission recently released the criteria for hosting the EMA, which is currently London based, after Brexit. Also up for grabs is the European Banking Authority.

Donald Tusk, the European Council president, and Jean-Claude Juncker, the president of the European Commission, have made it clear that minimising the disruption of services is “vital” and that the city finally chosen must ensure “business continuity” as the UK leaves the EU.

Almost every EU Member State has applied to host one of the two agencies, with some entering both ‘competitions’.

Copenhagen, Amsterdam, Milan, Stockholm, Barcelona and Dublin are all bidding for the EMA and more applicants are expected by the 31 July deadline.

The agency employs 900 qualified professionals and is a hub for pharmaceutical experts.

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 will be an official event held under the auspices of the Estonia Presidency of the EU, which runs from 1 July to the end of the year.

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 Congress, to be held at The Waterfront venue (pictured on page 4), 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 links below to read our more recent articles.

[Romania pushes for better access to personalised medicine](#)

[More fairness needed in access to personalised treatments](#)

[Access for all touted at haematology congress](#)

[Healthcare is for the many not the few, Theresa](#)

[Brexit talks must not undercut healthcare](#)



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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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