



European Alliance for Personalised Medicine

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5th annual conference takes on lung cancer

Welcome to our April newsletter. In Italy during the weekend of 25-26 March, on the occasion of the 60th anniversary celebrations of the signing of the Treaty of Rome, European Commission President Jean-Claude Juncker officially put forward his White Paper on the Future of Europe.

This turns the spotlight on a positive reform agenda, but what it doesn't do is particularly highlight the arena of health - which is surprising since the huge burden on the health services of all Member States promises only to get larger, rather than smaller.

Fortunately, other organisations in Europe are heading down the right path, including us. EAPM held its fifth annual conference at the prestigious Bibliothèque Solvay on Tuesday 28 March, which was preceded by a Maltese Presidency dinner and speeches in the European Parliament the night before.

The conference, sponsored by Siemens, Intel, Novartis, Medtronic and MSD Be well, and entitled '*Innovation, Guidelines and Screening: The Case of Lung Cancer*' took a close look at lung-cancer screening, although its general subject matter was broader than that, focusing on many of the issues that affect personalised medicine today. A report will follow in due course.

The World Health Organization has predicted that cancer will skyrocket over the coming decades - new cases of cancer globally are expected to increase by 70% over the next 20 years, from around 14 million to 25 million. A huge challenge. More than 130 high-level delegates and speakers attended the event, are more than prepared to meet it.

Of course, around about the same time as the conference was wrapping up, UK Prime Minister Theresa May signed the historic letter announcing Britain's intention to leave the EU.

By having this communication delivered to European Council President Donald Tusk on Wednesday, May formally paved the way for Britain to leave the EU in two years' time.

Many sectors look set to be affected by Brexit, not least the massive area of healthcare and, underlying that, the sharing of vital research and health data.

Indeed, at the conference, several delegates expressed a fear that the impact on healthcare options, especially in personalised medicine, would have huge implications for the bloc.

Stakeholders concerned with the healthcare of an ageing population, 500 million potential patients and a huge rise in co-morbidities across the EU were already facing a huge

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**
- **27-30 November: EAPM Congress, Belfast**

challenge. It is fair to say that the eventual departure of the UK is on balance a negative development.

Europe cannot afford to be negative, however. And it is up to stakeholders such as EAPM, plus decision-makers and political leaders across the remaining EU countries, to 'make-do-and-mend', seize what could be an opportunity for 'smarter' use of healthcare budgets, and move forward with a positive outlook.

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 R&D.

The Congress will see 35 parallel sessions plus ten presidential sessions. Here is a further link that readers should be aware of: to submit abstracts, click [here](#)

Meanwhile, the Editor-in-Chief of the Journal of Personalized Medicine (JPM), has announced the opening of the competition for the 2017 Travel Award sponsored by the journal. This consists of 800 Swiss Francs to attend a personalised medicine conference in late 2017, or early 2018. More details [here](#)

Meeting of Working Groups

EAPM held a meeting of several of its Working Groups in early March in order to set the political framework the Alliance wants to put in place between now and 2019.

This dealt with how to shape healthcare and to define the

priorities for the different groups. The meeting looked to determine how to facilitate scientific innovation and bring it to patients, including improving and speeding up the process of new medicine developments.

We have seen a great deal of new legislation (clinical trials, IVDs, data protection) but EAPM believes that there is still a lack of coherence at EU and national levels, plus a lack of alignment. The Alliance believes that it is important to communicate with one voice to the policy makers.

Some key points from the Regulatory Working Group were:

- Incentives are tools intended to develop and facilitate innovative treatments, being the foundation of industry research
- Developing a medicine takes between 5-8 years, and incentives support the risk of a process that is often long, a always expensive and can be difficult
- Member States express concerns about the availability of some drugs, their accessibility and prices. Incentives should look to provide accessibility and access to medicines
- EAPM will develop an academic publication on incentives related to personalised medicine which will be presented at the congress in November in Belfast

Points from the Working Group on Big Data included:

- The question of how to amplify the things that already exist and how to access to more data
- There is a need to have a European data ecosystem for personalised medicine, allowing for much better collaboration
- Despite there being national initiatives, the problem of how to put a network together still remains, as well as how to share the data given privacy restrictions and more

Some key points from the Working Group on Access were:

- The group covers a number of general topic such as differential



pricing, data driven examples, companion diagnostics and could focus on incentives, plus HTA and value

- The group should work towards optimising the value-based outcomes
- It is critical to consider the role of physicians to advocate and facilitate access for patients in the face of inequalities across Europe in terms of access. Cross-border collaboration remains vital
- The role of nurses is also important to consider, in particular their role with regard to patients
- The question remains of how patients understand personalised medicine and how they can be better informed about the quality of treatment

Getting our points across

At the very end of 2016, the World Health Organisation put forward its draft resolution on non-communicable diseases.

Not unexpectedly, the document put heavy emphasis on cancer, with the WHO already having estimated that cancer will rise hugely over the coming decades.

EAPM welcomes the WHO's efforts to address the challenge. It also embraces the draft resolution as a whole, but felt that some extra points need to be raised, and additions made.

Among them was our statement that without first identifying diseases at an early stage it is clearly more difficult to control and prevent them, and we put forward the addition of: 'to develop guidance, screening and tool kits to establish and implement comprehensive cancer prevention and control programmes.'

EAPM also believes that an international steering group of experts should be created to support this implementation and to check progress. But it must include patient organisations, so we proposed to: 'intensify collaboration with all stakeholders including patient organisations with the aim of scaling up cancer prevention and control and improving the quality of life of cancer patients.' These and other suggestions were

communicated to WHO in letter form, signed by co-chairs David Byrne and Gordon McVie.

Meanwhile, another letter - this time signed by MEPs - will be sent to the European Commission. EAPM is working with the STEP's MEPs' Interest Group as always, which strongly supports the setting up of a new Task Force on Big Data to develop further the Commission's digital strategy in health.

EAPM has already done much work via its Working Group on Big Data. Key among the Alliance's (and MEPs') aims is to substantially improve cooperation and collaboration among all stakeholders as well as encouraging all players to communicate better across inter-connecting areas in healthcare (and even within their own fields).

There is a wealth of data out there now, growing by the day. The letter will state that the MEPs and EAPM believe "we must remember that, in health, this information should revolve around, and give benefit to, the patient".

Further action for 2017

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**

Aside from this, 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/Member States as part of our ongoing outreach.



TEACH 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.

In the news

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

[All set for Brussels conference on personalised medicine](#)

[Change is coming – but not all for the best, it seems](#)

[Congress late November](#)

[Beating lung cancer against the odds](#)

[Are fake news and a post-truth world side-stepping fundamental realities? A question of values...](#)

[Slow-slow, quick-quick, slow. Health-care advances in Europe](#)



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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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