



European Alliance for Personalised Medicine

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Last call for EAPM conference

The Alliance's SMART approach

Welcome to EAPM's fourth newsletter of 2015 and, as you read this, we are drawing ever closer to the Alliance's third annual conference.

This will be held in on 2-3 June in Brussels under the auspices of the Latvian Presidency. More than 120 stakeholders have already registered and, as there is only limited time and space, we invite you to do the same as soon as possible by clicking [here](#).

This year sees two smaller nations at the helm of the European Union. Current president Latvia will be followed by Luxembourg on 1 July and EAPM is working with both to help further the cause of personalised medicine.

To this end, the forum will feature a number of high-level speakers, and the Alliance is delighted to announce that these will include the **health ministers from Latvia and Luxembourg, as well as the health minister from Malta**.

On top of this, several, cross-party Members of the European Parliament will also be attending the conference.

EAPM believes that health policies need to recognise and tackle the inherent health system vulnerabilities faced, specifically, by smaller countries and in the regions of the larger ones.

We call this a **SMART** approach – **Smaller Member States And Regions Together**; and this will be further developed at the conference, entitled 'Smaller Member States And Regions Together (SMART)': STEPs in the Right Direction to a Brave New Healthier Europe'.

At this flagship event, personalised medicine's most influential stakeholder representatives will take part in six plenary sessions, and the topics covered will be:

May and June at a glance:

- **May:** Finalisation of the White Paper on 'Value of Diagnostic Information for Personalised Medicine'

- **2 June:** Press conference to launch PerMed's Strategic Research and Innovation Agenda (SRIA) report, in the company of MEPs Cristian Busoi and Marian Harkin.

This will be held at the Brussels European Parliament and also present will be PerMed Coordinator Dr. Wolfgang Ballensiefen and patients' representative Louis Denis

- **2-3 June:** EAPM annual conference - 'Smaller Member States And Regions Together (SMART)': STEPs in the Right Direction to a Brave New Healthier Europe'

- 'State of Play' of ensuring better treatments for patients
- Learning from Smaller Member States and Regions
- Medical Adaptive Pathways – Taking Steps Forward
- Strengthening Patient-orientation and Personalisation: Overcoming Barriers to Equality and Solidarity: Patient Access
- Personalised medicine and a European Big Data-driven economy – The Lighthouse Effect
- Unlocking the value of research to provide evidence, and education of healthcare professions

The sessions, representative of EAPM's membership (patients, medical professionals, healthcare planners, industry, scientists and researchers), reflect the solid work programmes developed since the Alliance's formation and, from these discussions, a set of recommendations will emerge which EAPM hopes will support and strengthen Luxembourg's Council Conclusions on Personalised Medicine due later in the year.

It promises to be a lively and productive two days and we hope to see you all there.



EU2015.LV

Latvian Presidency
of the Council of the
European Union

Read all about it...

As ever, during the past weeks and months, the Alliance has been working to spread the word and explain the benefits of personalised medicine to the wider world.

A number of our recent articles can be found by clicking on the titles below.

[Is precision medicine the route to a healthy world?](#)

[The value to Europe of harnessing 'Big Data'](#)

[Personalised medicine: An unstoppable force for good](#)

[Time to reboot the EU's health programme](#)

[Levelling the playing field for Europe's patients](#)

[Affordable health care in testing times: The way forward -](#)

[Data co-operatives: Giving BIG choices to the patient](#)

[Time to 'STAMP' out lack of access to new treatments](#)

Also worth checking out in the run-up to 2-3 June is our conference website, which you can visit [here](#), while the current conference booklet can be viewed [here](#).

EAPM in action

On the morning of the first day of the forum, in the European Parliament in Brussels, EAPM will host a press conference to launch **PerMed's Strategic Research and Innovation Agenda (SRIA) report**, in the company of MEPs Cristian Busoi and Marian Harkin.

Also present will be PerMed Coordinator Dr. Wolfgang Ballensiefen and patients' representative Louis Denis.

PerMed is a Coordination and Support Action (CSA) of 27 partners, financed by the European Commission and representing patients' interests as well as decision makers in research policy, health care and implementation.

It is tasked with generating recommendations and research activities aimed at fostering the further implementation of

personalised medicine – a fast-emerging method of treating patients on an individualised basis that is largely based on genetic make-up.

The SRIA to be presented on 2 June is based on an analysis of several recent strategic reports, plus interviews and consultations with experts and representatives of all relevant stakeholders in the arena of personalised medicine.

The SRIA has examined current challenges before suggesting prioritised recommendations with the highest potential in facilitating the introduction of this exciting new form of treatment.

The report's recommendations include an urgent need to demonstrate the impact and potential benefits of personalised medicine for health systems.

This will be achieved by supporting public health evaluations; incorporating patient participation and responsibility in all phases of research and development and in the ownership and control of personal health data, and; developing common principles and regulatory frameworks that enable the ethical sharing of personal data for research.

Other recommendations highlight the need to: promote the development of high-quality sustainable databases; support translational research infrastructures and enforce data harmonisation; develop new decision-support tools and methodologies to analyse and interpret data, and; better integrate and evaluate information provided by genomic, epigenetic, transcriptomic, proteomic and metabolomic analyses.

Also vital is the development of new clinical trial designs as well as a systematic early dialogue between innovators, citizens and decision-makers throughout all regulatory steps.

These recommendations will be described and explained further at the press conference.

The Alliance has also called for the development of a European Translational Research Platform (ETRP) that enables the efficient conversion of exciting research discoveries to innovative diagnostics, therapeutics, products and processes that will benefit European patients, industries and societies.



SMART

Smaller Member States And Regions Together

White Paper, surveys and more...

Meanwhile, EAPM has been working on a number of updates to documents developed by the Working Groups on Regulatory Affairs and Big Data.

And alongside the chairs of the Clinical Trials consensus group, the Alliance is compiling detailed feedback from the members. Discussions will continue over the coming weeks.

EAPM has also produced a draft White Paper entitled: **The Value of Diagnostics to Patients and Payers in the Personalised Medicine Era**. This represents an outcome of the workshop entitled **The Value of Diagnostic Information for Personalised Medicine** which was held on 25 February in the presence of the European Commissioner for Health, as well as a survey undertaken with patients/payers.

As a result, EAPM has developed a short paper which has now been circulated. If recipients have any additional comments, please include these in track changes and send it back to us by 11 May.

A further survey is in the pipeline on the topic of national cancer plans. As part of its mission to embed personalised medicine into health systems at national level, EAPM's survey is investigating the current degree of personalised medicine's integration into National Cancer Control Programmes (NCCPs).

The EU is committed to reducing the burden of cancer in Europe, through initiatives such as the European Partnership for Action Against Cancer (EPAAC) and the Joint Action on Comprehensive Cancer Control (CanCon).

One of the key aims of EPAAC was to support Member States in their development of new NCCPs or enhancement

of existing NCCPs. EPAAC members have collected a significant body of data and developed a great deal of expertise in the area of national cancer policy and its implementation in the EU. The data has revealed significant differences in NCCPs across Member States.

Personalised medicine, with its promise of delivering 'the right treatment to the right patient at the right time' is particularly relevant in the context of cancer. However, at a policy level, it was not positioned as a strategic priority when many of the NCCPs were designed and implemented.

This survey attempts to capture the current status of personalised medicine within NCCPs and the Alliance will subsequently use the information to help enhance personalised medicine's integration into future cancer care pathways.

The results of the survey will be presented at the upcoming EAPM conference..

The Alliance is also working on the establishment of an Expert Group, provisionally called **Data-SPHERE**, which stands for **Data Support and Policy for Healthcare in Europe (Results and Empowerment)**.

The European Commission has concluded that the EU needs a more comprehensive and coherent policy on the fundamental right to personal data protection, as the current framework has not prevented fragmentation in the way personal data protection is implemented across the EU.

There is also legal uncertainty and a widespread public perception that there are significant risks associated with the sharing of health research. Data-SPHERE will attempt to address these issues.



Meanwhile, the Alliance has developed a paper on the subject of a **Lighthouse Initiative for Personalised Medicine**, which EAPM is pushing to be included in the Big Data Value Partnership.

The creation of the Big Data Value Association and the European contractual Public Private Partnership (cPPP) on Big Data Value brought forward two powerful vehicles to support the development and adoption of data-centric initiatives that can contribute positively to the socio-economic and technological progress of Europe.

A focus on personalised medicine would be very beneficial to Europe as it has massive potential to make treatments more effective (with fewer side effects) and more cost effective.

Discussions with the European Commission are ongoing in this respect.

Elsewhere, regarding the recent the Personalised Medicine Literacy Survey, which readers will recall was targeted at leading healthcare professionals, the Alliance received more than 85 replies from across the medical professional community.

The results of this online survey will be compiled this month and will augment EAPM's overall activities in relation to the education strategy for healthcare professionals in the personalised medicine community.

Meanwhile, talks are underway with The Netherlands' EU health representative regarding the country's six-month presidency in 2016, while the Alliance's engagement with MEPs continues unabated.

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 European Medicines Agency. EAPM is funded by its members.

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