



Belfast Bulletin: 29 November 2017

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Research should be the 'key driver' in PM

Day Two of our Congress is now behind us and focus now turns to today's events, highlights of which you can read on the following pages.

But before that, it's time for a quick recap on one of yesterday's key sessions, entitled *Research Frontiers in Personalised Medicine*.

Panel co-chair Mairead O'Driscoll, of the Health Research Board of Ireland and IC-Per Med was first to speak at the session. She said that the overall aim of modern research should be "to foster EU collaboration involving parties, promote open research and then put research into practice".

"Research should be the key driver in personalised medicine," she said, adding: "We must bring personalised medicine to the citizens of Europe."

Peter Keeling, of Diaceutics, said that research "should be all about pairing therapies with diagnostics.

"We all have friends and relatives who have been or are patients - they've probably been subjected to a type of medicine that has been a little tested and then used to treat everyone broadly the same.

"That has benefited us over the years in the evolution of treatment but more recently, with a technology revolution going on, genetics, and other types of testing, we are really able now to find much better types of patients in the same disease.

"The pharmaceutical industry has been able to laser-focus treatments on those different types of disease."

Stéphane Hogan, head of sector for neuroscience with DG Research & Innovation of the European Commission, said: "As far as research is concerned, the possible next steps in the value of treatment project - such as exploring the application of the developed methodology to other disease areas e.g. rare diseases or chronic pain - as well as a future focus on interventions such as rehabilitation, is essential."

In the final analysis, the panel agreed that the research frontiers in personalised medicine were there to be exceeded and surpassed - and that the future held much in terms of discovery and progress.

Today's highlights at a glance

- **Health Literacy: A Key Component of Personalised Health and Innovation**
- **Genomics, DNA and Diaspora**
- **Crossing the Value Rubicon in Precision Care**
- **Irish experience and special performance evening**





Congress speakers and delegates gathered last night at the Titanic Belfast for a gala dinner and the inaugural HI-5 awards. Photo by Simon Pugh Photography

HI-5 Awards raise Titanic

Attendees saw five recipients pick up the inaugural HI-5 awards at the Titanic Belfast last night (Tuesday).

The term 'HI-5' represents the health innovation five, and the first-ever awards were given in the following EU-based categories:

- Region that has done the most to support innovation
- Best research centre for innovation in personalised medicine
- Best hospital for integrating personalised cancer medicine
- Company which has done most to promote personalised healthcare
- Best minister/politician supporting health innovation in personalised medicine

The first award went to Regione Lombardia, home of the Italian city of Milan, with the Institut Gustave Roussy in Villejuif, France, landing the EU-based research centre for innovation prize.

The honoured hospital was Vall d'Hebron Institute of Oncology in Barcelona, while pharmaceutical giant Roche won the best company to promote personalised healthcare award.

No individual won the political award. Instead, it went to a group of Members of the European Parliament in recognition of their work done in promoting access to personalised medicine. This award was collected on their behalf by Mary Baker, a past president of the European Brain Council.

Judge Fidelma Macken, a former judge of the Supreme Court of Ireland and European Court of Justice, gave the keynote speech at Titanic Belfast, where delegates had gathered for a gala dinner and the awards ceremony.

The evening was presided over by Denis Horgan and Gordon McVie, executive director and co-chair of EAPM respectively, and the awards were presented by Peter Meeus, Head of Region

Europe, Shire, Richard Sullivan, of King's College London, James N'Dow, Guidelines Office Board at the European Association of Urology, and Mary Baker, a past president of the European Brain Council.

The previous evening had seen two initial awards presented at a welcome reception of the Congress attendees at Belfast City Hall.

The EAPM SMART Award (Smaller Member states And Regions Together) went to Malta, while the Patient-centric Innovator Award went to AstraZeneca.

The Hon. Christopher Fearn, Minister of Health for Malta, picked up the SMART Award from Peter Meeus, while David Boyd picked up the AstraZeneca prize from Stephen McMahon, president of the Irish Patient Association.

EAPM general meeting

Yesterday, the Alliance held its Annual General Meeting in the boardroom at the Waterfront venue.

Joining the board is Dr. Jasmina Koeva-Balabanova, founder and chair of the Bulgarian Alliance for Precision and Personalized Medicine (BAPPM).

The meeting also confirmed the venue and dates of the second EAPM annual Congress, which will be held in Milan, Italy, from 26-28 November 2018.

In the interim, the Alliance will place a key focus on prevention, screening and early diagnosis, while continuing its SMART Outreach programme to take in the cities of Berlin, Paris and Vienna among others.

Earlier today

Presidential Session: Is precision medicine the route to a healthy world?

The EU has long displayed a willingness to explore the best path

A 'HI-5' to the best in personalised medicine!



Above: EAPM co-chair Gordon McVie with Marina Gerini of the Lombardy Region. Above and to the right is former judge Fidelma Macken who spoke at the networking event.

Photos by Simon Pugh Photography





European Alliance for Personalised Medicine



Peter Keeling, of Diaceutics, spoke in the session 'Research Frontiers in Personalised Medicine'. Photo by Simon Pugh Photography

among many competing paths, to favour discussion and debate rather than destructive dissent.

It has established mechanisms of communication, has found terms and modalities to negotiate, to compromise, to create a common tongue with a sense of shared values.

During the first presidential session of the third day of Congress, the key speakers got to grips with precision medicine.

James N' Dow, chairman of the Guidelines Office Board at the European Association of Urology in the Netherlands, was strident about what he felt needed to be done: "We have more than enough data in the medical world, but we don't share enough of this data. We must align stakeholders' interests with our common goal, namely the very best health care that can be provided."

Mary Baker, who is a former president of the European Brain Council, said: "If pharma companies pursue that they're solely patient-led, patient focused, patient-centric, they won't be able to deliver.

"Although the patient experience is extremely important, they should not be the sole focus. We need to look at the broader needs of society. A more sustainable approach is to look at prevention. We need to start concentrating seriously on prevention, where pharma has a huge role to play and has had great success with vaccination programmes."

Precision medicine allows doctors and researchers to predict more accurately which treatment and prevention strategies for a particular disease will work in which groups of people.

It is in contrast to a one-size-fits-all approach, in which disease treatment and prevention strategies are developed for the average person, with less consideration for the differences between individuals.

Although the term 'precision medicine' is relatively new, the concept has been a part of healthcare for many years.

For example, a person who needs a blood transfusion is not given blood from a randomly selected donor; instead, the donor's blood type is matched to the recipient to reduce the risk of complications. Although examples can be found in several areas of medicine, the role of precision medicine in day-to-day healthcare is relatively limited. Researchers hope that this approach will expand to many areas of health and healthcare in coming years.

Points to consider:

- *Personalised medicine offers the promise of healthcare moving away from 'trial-and-error' therapies to evidence-based individual ones, removing the outdated 'one-size-fits-all' philosophy.*

- *Down the line, healthcare services will increasingly deliver the right intervention when appropriate, improving the outcomes for patients and cutting down on unnecessary treatments.*

Quotes from the sessions



"We need to build bridges between genomics and medicine so that the shift between research to practicing medicine can become a reality."

*Ewan Birney,
European Bioinformatics Institute*



"Citizens and patients will be key players of Big Data. They are the first aggregators of data and must therefore participate in scientific research. It goes beyond the question of consent."

*Ernst Hafen,
ETH Zurich*



"Too often, regulatory agencies, governments, and funding agencies do not stimulate the integration of research into care and vice versa."

*Denis Lacombe, Director General,
European Organisation for Research and Treatment of Cancer*



"One of the main challenges that arises when it comes to the manufacturing of precision medicines, is the location of the production."

*Killian O'Driscoll,
NIBRT, Dublin*



"Research should be carried out 'with' or 'by' members of the public, not 'on' or about them."

*Mairead O'Driscoll,
Health Research Board of Ireland,
IC-PerMed*

Patient story - rare cancer

A 53-year old patient, MD, living in Luxembourg, told EAPM in the run-up to this Congress that she is optimistic that healthcare is moving in the right direction.

This was partly based on the fact that her 29-year-old son recently took advantage of cross-border treatment when suffering from a rare cancer, and this came about through long and fruitful discussions with healthcare professionals resulting in shared decision making.

The results so far, MD says, were well worth the time that she herself had to take off work and the travel involved.

The Luxembourger also feels that different, and more modern, models for clinical trials helped in her son's case (as there are, by definition, fewer rare cancer sufferers) and that revisions to data protection laws will mean that her son's health data should be available to help researchers and, ultimately, other patients down the line.



Peter Meeus of Shire. Photo by Simon Pugh Photography

- Personalised medicine starts with the patients, and holds huge potential for improving the health of many of them.

Coming up...

Health Literacy: A Key Component of Personalised Health and Innovation

One of the key goals in the personalised medicine era is to improve communication between front-line healthcare professionals and their patients.

The latter should have an equal role in any decisions made about their treatment, and this requires them to be able to input vital information, such as lifestyle and work circumstances, as well as to be properly informed from the other side. Discussions should be a two-way street.

To help facilitate this, it is more important than ever to bring Europe together in a way that improves the already significant skills that healthcare professionals possess to permit co-decision-making which will effectively empower the patient.

Clearly, the healthcare professional is trained to be an expert in diagnosing conditions and suggesting treatments. And yet

the patient also knows more about his or her own lifestyle, work environment and how much he can rely on family-care resources, for example, so co-decision is a growing part of modern-day medicine.

Ultimately, the two must work together to produce the optimal result.

Core aims include:

- An overall structure is needed to achieve shared understanding among healthcare professionals, patients and the public.
- Education and training that is high quality, transparent and transferable will be needed for the cross-disciplinary approach vital to translating personalised medicine into clinical practice.
- Success will require higher levels of health literacy among patients and the wider population, as well as readiness - and skills - among healthcare professionals to engage more closely with patients over treatment issues and options.
- Hospitals and labs should be adequately equipped with competent personnel and medical technology needed to deliver on the promise of personalised medicine, such as to permit biomarker testing in an efficient and timely manner so as to allow a drug/diagnostic combination to be of benefit to patients.
- Awareness is needed amongst physicians, so coordinated, interdisciplinary collaboration is required to ensure that health professionals are educated in the field.

Genomics, DNA and Diaspora

Giant leaps in genetics have advanced certain key areas in medicine, (drugs and treatments, both) and have also shed light on what we might think of as anomalies.

These days, there is more co-decision as lifestyle, work and personal preferences come into play – especially with front-line healthcare professionals who are up-to-speed with the latest developments, or know where clinical trials are taking place.

Of course, the quality of treatment varies from country-to-country, depending upon resources and incidence





James N' Dow, chairman of the Guidelines Office Board at the European Association of Urology in the Netherlands. Photo by Simon Pugh Photography



Elko den Breejen of Roche. Photo by Simon Pugh Photography

of a particular disease, and the awareness (or not) of potential over-treatment.

Patients are, for sure, not experts on medical matters. But they are absolute experts on their own lifestyles. Some doctors still don't get that, and it needs to change.

We are not in a position (yet) to change a person's genetic make-up to remove the possibility of a specific disease - although certain immunotherapy methods are coming to the fore which better target treatment - but these leaps in genetics-based sciences are moving us forwards quickly.

Core aims include:

- Agree standards for genomic sequencing and analysis, and around the sharing of genomic and associated clinical data.
- Promote the uptake and alignment of existing agreed

standards and define standards for interoperability of health informatics systems.

- Coordinate national activity to ensure best practice emerging with regards to clinical implementation and application is shared.
- Structure a training programme in genomics, informatics and personalised medicine for healthcare professionals.
- Promote broad discussion with European regulators on the appropriate regulatory mechanism for clinical genomic testing.

Crossing the Value Rubicon in Precision Care

There is room for improvement for optimally bringing the latest science to the patient while taking into account patient priorities such as quality of life.

Too often, regulatory agencies, governments, and funding



Banner headlines: EAPM makes a splash outside the Waterfront congress venue in Belfast. Photo by Simon Pugh Photography

agencies do not stimulate the integration of research into care and vice versa.

Re-engineering the drug development process is a priority, and healthcare systems are long due for transformation.

On one hand, patients need efficient access to treatments, but despite precision oncology approaches, efficiently shared screening platforms for sorting patients based on the biology of their tumour for trial access are lacking and, on the other hand, the true value of cancer care is poorly addressed as central questions such as dose, scheduling, duration, and combination are not or sub-optimally addressed by registration trials.

Solid evidence on those parameters could potentially lead to a rational and wiser use of anti-cancer treatments. Together, optimally targeting patient population and robust comparative effectiveness data could lead to more affordable and economically sound approaches.

The drug development process and healthcare models need to be interconnected through redesigned systems taking into account the full mathematics from drug development into affordable care.

Key points to consider:

- *Patient empowerment can be a vital element of high-quality, sustainable, equitable and cost-effective health systems.*
- *Important challenges in European health are demographic change and the long-term consequences of the financial crisis. Yet there is a need to secure access to, and affordability of, healthcare. Technological and social innovations are needed to empower the health system, the citizen and patient.*
- *It is time for a fundamentally new strategy with maximising value for patients at its centre by achieving the best outcomes at the lowest cost.*

● *The fragmented system must be replaced with one in which services for particular medical conditions are concentrated in health-delivery organisations in order to deliver high-value care.*

● *As the landmark Luxembourg Council Conclusions on personalised medicine stated, the EU should: "take into account, inter alia, added value from the patient's perspective as well as enhanced cooperation and exchange of best practices".*



Sign of the times: visitors to the Congress



Angelina Thomas (top left), Darragh McArt (r), middle Ellen De Waal, bottom left Jens Rauch, bottom right Patrick Mooney.
Photos by Simon Pugh Photography



Twitter hashtag for this Congress:
[@eapm2017](https://twitter.com/eapm2017)



European Alliance for
Personalised Medicine

*In close collaboration
with our partners:*



Estonian Presidency
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Platinum partners:



Gold partners:



Silver partners:



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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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