

Personalised medicine: building a patient-centric Europe

The citizens of the future will be increasingly informed about, and engaged in, their own healthcare. Regulators must make it possible to allow patients early access to novel and efficient treatment.

Together we can transform our healthcare system into one that delivers the best care for patients, empowers them, puts research and innovation at their service, and gives the best possible value. But the right conditions must be in place.

Empowering patients depends upon each being treated as an individual, taking into account not only the illness but also differing social and cultural backgrounds.

The patient needs to be involved in every aspect of treatment. Education and simplified, standardised information, plus full access to all relevant medical files, are cornerstones of this. The patient should have access to all possible treatments.

With the support of the European Commission and Parliament we can make this happen. It is the responsibility of all of us and all stakeholders must devise an aligned strategic research agenda, with input from all disciplines but including the patients.

All EAPM members (patients, medical professionals, healthcare planners, industry, scientists and researchers) share the vision of a Europe which inspires trust in its health systems. Unnecessary deaths of patients could be avoided via greater access to innovative treatment and diagnostics and efficiently organised research.

With this in mind, the European Alliance for Personalised Medicine draws your attention to its ongoing STEPs campaign, which stands for Specialised Treatment for Europe's Patients. See the back page for more details.

EAPM's initiative calls on Europe's decision-makers to commit to the following STEPs for 2014-2019:

- **STEP 1: Ensuring a regulatory environment which allows early patient access to novel and efficacious personalised medicine (PM)**
- **STEP 2: Increasing R&D for PM, while also recognising its value**
- **STEP 3: Improving the education and training of healthcare professionals**
- **STEP 4: Supporting new approaches to reimbursement and HTA, required for patient access to PM**
- **STEP 5: Increasing awareness and understanding of PM**

EAPM believes that achieving these goals will improve the quality of life for patients in every country in Europe.



European Alliance for
Personalised Medicine

An introduction to EAPM, its Policy Taskforces and STEPs campaign



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About EAPM

The European Alliance for Personalised Medicine (EAPM) 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.

EAPM was launched in March 2012, as the European discussion on personalised medicine gathers pace. It is a response to the need for wider understanding of priorities and a more integrated approach among distinct lay and professional stakeholders. It works on case studies, education, training and communication to deliver practical policy recommendations designed to exploit the potential of personalised medicine to the full.

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.

By bringing together all stakeholders, EAPM's aim is to help to forge constructive links between the EU institutions and society.

The EAPM Forum brings all members together every 2-3 months to review activity and to direct political strategy. Working groups develop positions on key topics and make proposals and recommendations to the Forum.

The secretariat manages day-to-day operations, prepares Forum meetings, and co-ordinates the working groups. EAPM is funded by its members.

Policy Taskforces - Making a difference in Europe

EAPM has five main Policy Taskforces:

Big Data

Chairs: Mario Romao, INTEL;
Bonnie Wolff-Boenisch, Science Europe

Key Policy Ask: "By 2020, the EU should endeavour to achieve widespread benefits for patients and citizens from personalised healthcare by defining in 2015, and subsequently executing a Data Strategy for Personalised Medicine" (EAPM, 2014)

Education and Training of Healthcare Professionals

Chair: Thom Duyvene de Wit, EHA

Key Policy Ask: "By 2020, the EU should support the development of a Europe-wide education and training of healthcare professionals' curriculum for the personalised medicine era, by committing to this in 2015. The EU should subsequently facilitate the development of an Education and Training Strategy for HCP in Personalised Medicine"

Early Access and Better Decision Making

Chair: Ansgar Hebborn, ROCHE, Kaisa Immonen-Charalambous, European Patient Forum

Key Policy Asks: to ensure: a) healthcare resources allocated to development and utilisation of personalised medicine, through acceptance of its long-term cost-effective benefits and b) to effect a paradigm shift in pricing and reimbursement to recognise the societal value of a medicine



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Research Roadmap for PM

Chair: Mark Lawler, Queen's University Belfast

Key Policy Ask: For the EU to commit to the development of a European Translational Research Platform that enables the efficient translation of research discoveries to innovative diagnostics, therapeutics, products and processes that will benefit European patients, industries and societies

Regulatory Taskforce

Overall Chair: Anastassia Negrouk, EORTC

There are four thematic focuses in this WG.

Stream 1: Clinical Trials

Policy Ask: To ensure a responsive regulatory environment that responds to the needs of all stakeholders whilst ensuring patient safety, with the end result of ensuring development of treatments for patients

Stream II: Data Protection

Policy Ask - easier circulation and sharing of personal data, appropriately balanced with personal privacy for the benefit of patients

Stream III: In-Vitro Diagnostics

Policy Ask: greater attention to the role of diagnostics and imaging in personalised medicine

Stream IV: Medical Adaptive Pathways

Key Issues: A) There is a need for a better understanding of patients' and payers' willingness to operate with greater uncertainty driven by the release of needed therapies with less evidence at the initial launch;
B) there is a need to facilitate the IT infrastructure and processes to provide the necessary evidence base using real-world data