

The International Consortium for Personalised Medicine

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International Clinical Trials Day, ECRIN, Paris, May 20 2019



Personalised Medicine – A definition

*Personalised Medicine [] “refers to a medical model using characterisation of individuals’ phenotypes and genotypes (e.g. **molecular profiling, medical imaging, lifestyle data**) for tailoring the right **therapeutic strategy** for the right person at the right time, and/or to determine the **predisposition** to disease and/or to deliver timely and targeted **prevention**”.*

According to: Horizon 2020 and
European Council Conclusions on personalised medicine for patients (2015/C 421/03)

Context for Personalised Medicine

- **Technology:** digital revolution in health; access to and linking of large databases; “omics” technologies; novel computational approaches for analysis and interpretation of complex data;
- **Approach to healthcare:** focus on patient, through extensive individual profiling; drive towards prevention and early intervention;
- **Sustainability of healthcare systems:** increased costs and complexity; better use of resources through prevention, early diagnosis and improved therapeutic efficacy;
- **Societal expectations:** more informed and engaged patients; expectation of improved health-related quality of life;
- **Opportunities:** for patients, health care provider, payers, industry.

Key activities & milestones leading to ICPerMed

- 2010** **Workshops** on ‘omics’ research in Personalised Medicine, organised by the European Commission (EC)
- 2011** **Conference** *European Perspectives in Personalised Medicine* organised by EC
- 2011** Establishment of the **EuroBioforum**, a platform for funders and performers in PM fostering dialogue and cooperation (FP7)
- 2013** **PerMed**, an EC funded Coordination and Support Action (FP7) to develop an agenda for PM
- 2015** *Shaping Europe’s Vision for Personalised Medicine - Strategic Research and Innovation Agenda (SRIA)* with comprehensive recommendations for PM implementation
- 2016** **Personalised Medicine Conference** organised jointly by the EC and representatives of member states

ICPerMed – An International Consortium

Need of a mechanism to support:

- **Coordination:** map ongoing activities, align research and funding activities, provide a forum to explore policy recommendations
- **Collaboration:** general support for collaboration in Personalised Medicine space
- **Creation of synergies:** collaboration between funders to create synergies and avoid overlaps

November 2016 - Launch of ICPerMed, funding of the ICPerMed Secretariat CSA

ICPerMed aims:

- Establish **Europe as a global leader** in personalised medicine research
- Support the **personalised medicine science base** through a coordinated approach to **research**
- Support research to investigate **the benefits** of personalised medicine to **citizens** and **healthcare systems**
- Pave the way for personalised medicine approaches for **citizens**

Research as a driver of personalised medicine

ICPerMed – An International Consortium

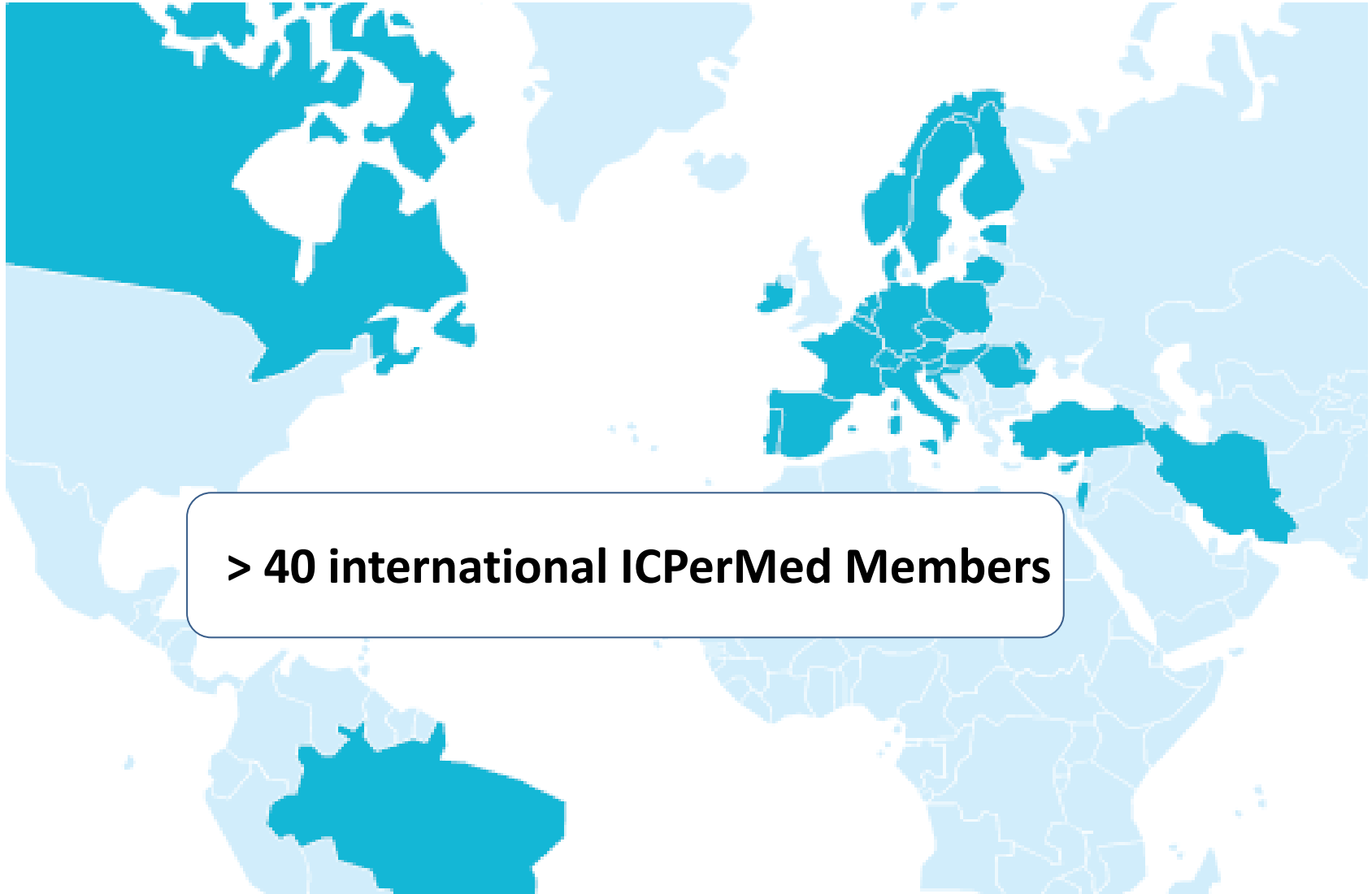
Platform to support exchange and align and encourage efforts on personalized medicine research, funding and implementation:

- meetings, workshops and congresses
- mapping personalised medicine programmes, best practices and actions
- strategic publications
- joint initiatives

ICPerMed – an international consortium

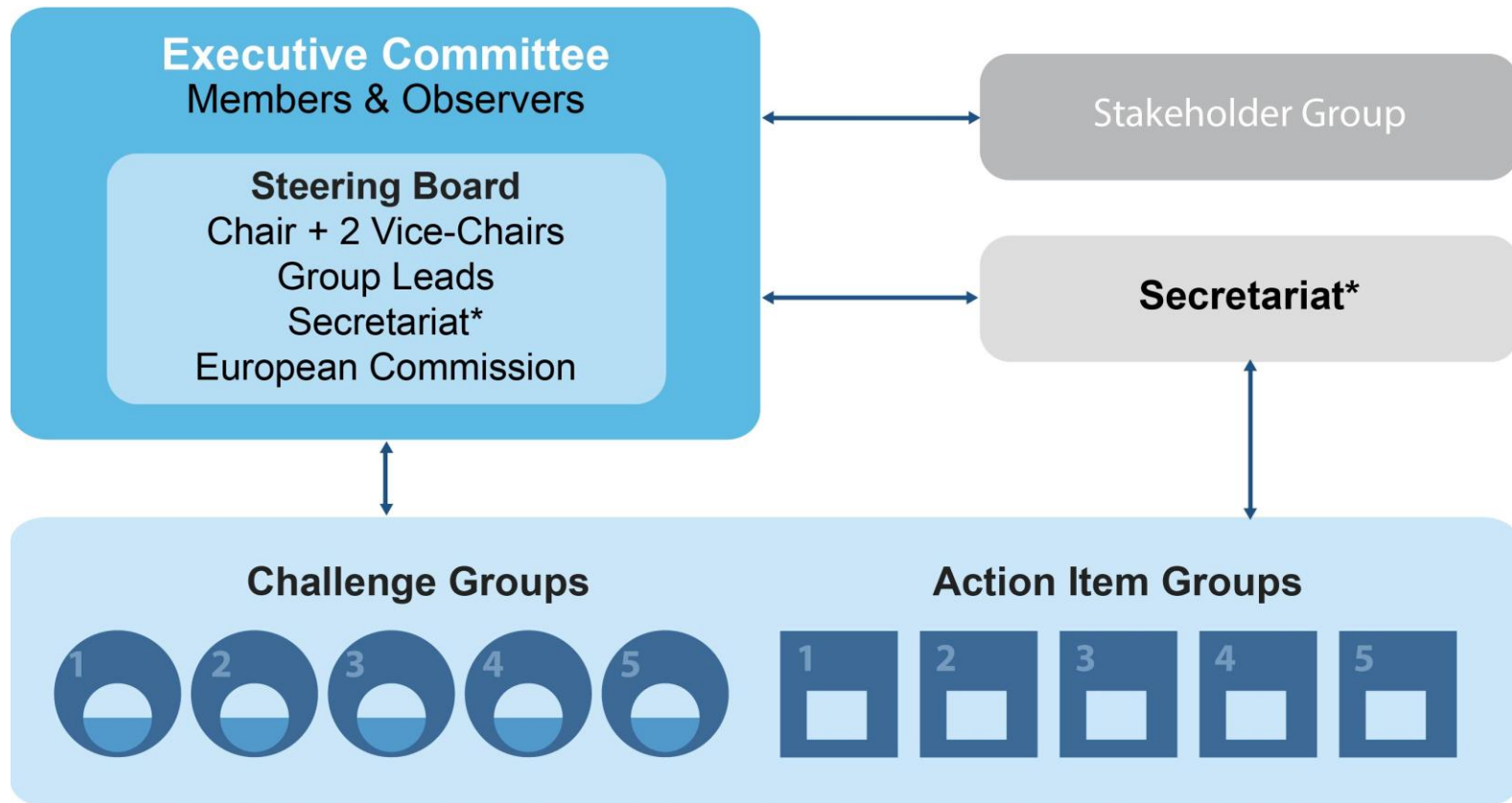
- Member state-driven, international consortium model
 - Identify common strategic goals
 - Align research funding
 - Share results, data, standards and best practices
- > 40 members representing policy organisations (ministries of health, science or other), research funding agencies

ICPerMed members:



> 40 international ICPerMed Members

ICPerMed Governance

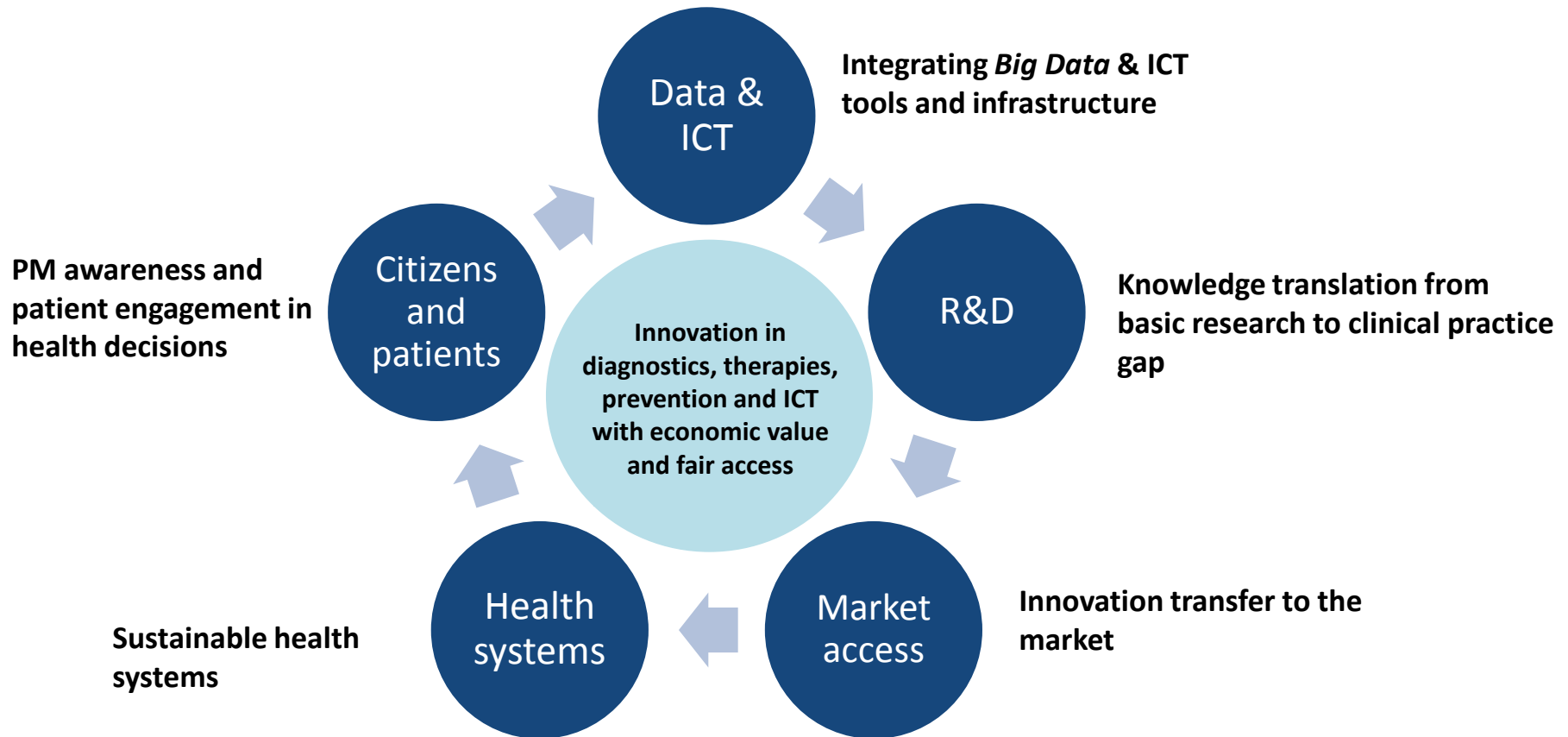


* The Secretariat is a Coordination and Support action funded by the European Union's Horizon 2020 research and innovation programme under grant agreement no. 731366.

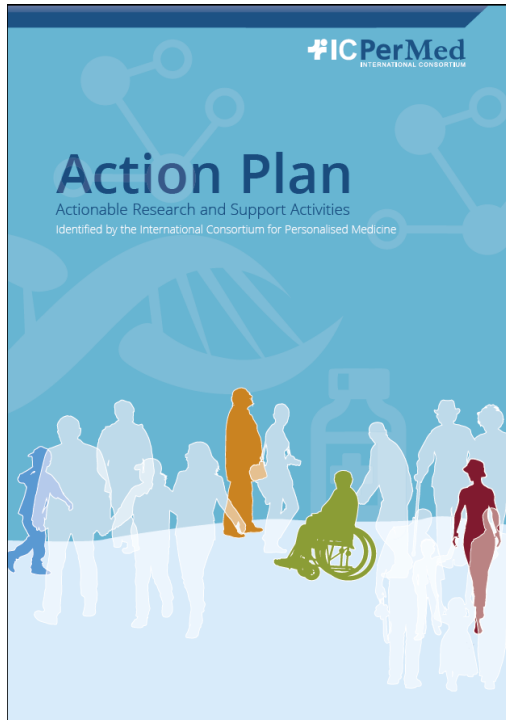


ICPerMed Challenge Groups

Define topics across the whole healthcare value chain to advance PM



ICPerMed Action Plan



- Actionable research and support activities
- To inform national and European strategic discussion of research funders

Released in March 2017

www.icpermed.eu

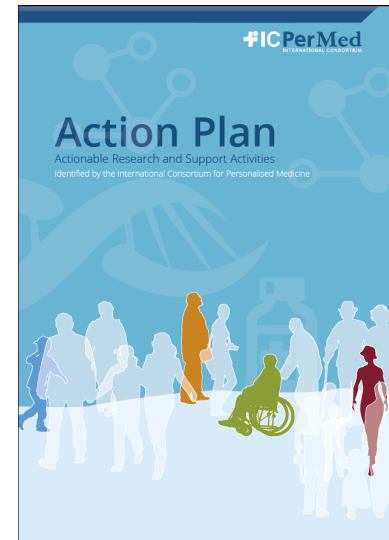
ICPerMed Action Plan

A) Research Activities (22 Action Items)

- **Data:** Sharing, harmonization, integration, decision support tools
- **Technologies, Methods and Processes:** pre-clinical models, clinical trials, regulation, health economics, disease classification
- **People:** literacy, citizen engagement
- **Cross-Cutting:** ELSI

B) Research-support Activities (8 Action Items)

- **Infrastructures:** databases, biobanks, cohorts
- **Methods and Processes:** instruments for sustainable health systems
- **People:** education of professionals



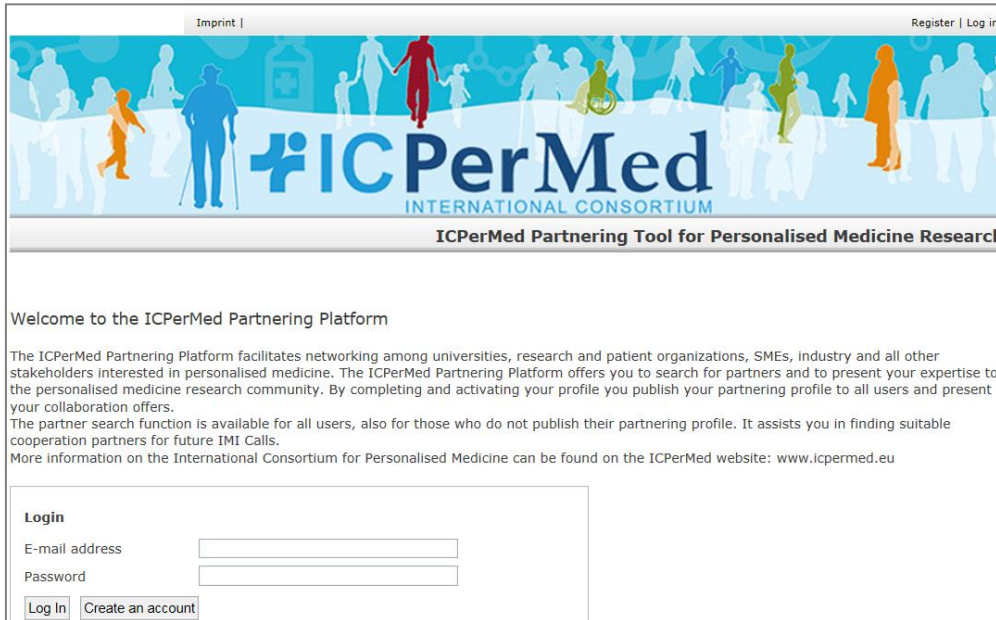
Action Item Groups – implement Action Plan

- 1) Data and ICT – Enabling Technology
- 2) Data and ICT – Improving Health Care
- 3) Translational Research
- 4) Health Economics, Regulation & Market Access
- 5) People and Society

Analyse and report on the implementation of the Action Plan:


- Collection of ongoing activities of the members and beyond
- Identification and dissemination of best-practice examples
- Development of potential common future activities.

ICPerMed Partnering Tool



- A **Partnering Tool** to identify and contact potential cooperation partners
- The platform has already been utilised by the ERA-PerMed and the Flagship Canada/EU call
- ~ 300 entries so far

Survey and Database



Welcome to the ICPerMed mapping database - funding for research in Personalised Medicine

The ICPerMed database gives an overview on the actions in the field of Personalised Medicine (PM) performed in the ICPerMed member states and may assist you in finding suitable funding opportunities and information about potential funders in your respective country and/or region.

Via the ICPerMed database, ICPerMed members (e.g. funding agencies and ministries) provide available information about their national/regional funding activities in PM. The different national/regional funding schemes and general funding information are described. The database allows the user to search for programmes susceptible to finance research projects in the field of PM. This includes not only programmes that are ongoing but also those that are already completed as well as others that will start in the near future.

The ICPerMed database is open to the public after simple registration.

The ICPerMed database reflects the progress of the ICPerMed consortium towards the objectives and implementation of the ICPerMed Action Plan. More information on the International Consortium for Personalised Medicine (ICPerMed) can be found on the ICPerMed website: www.icpermed.eu.

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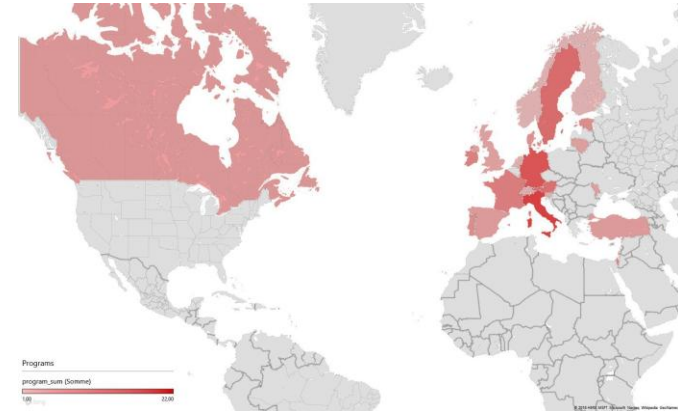
[Forgot your password? Register](#)

- Mapping Activity: Ongoing funding programmes in PM
- Survey was sent to all ICPerMed members
- Results are available in the ICPerMed mapping database
- Open to the public after a simple registration

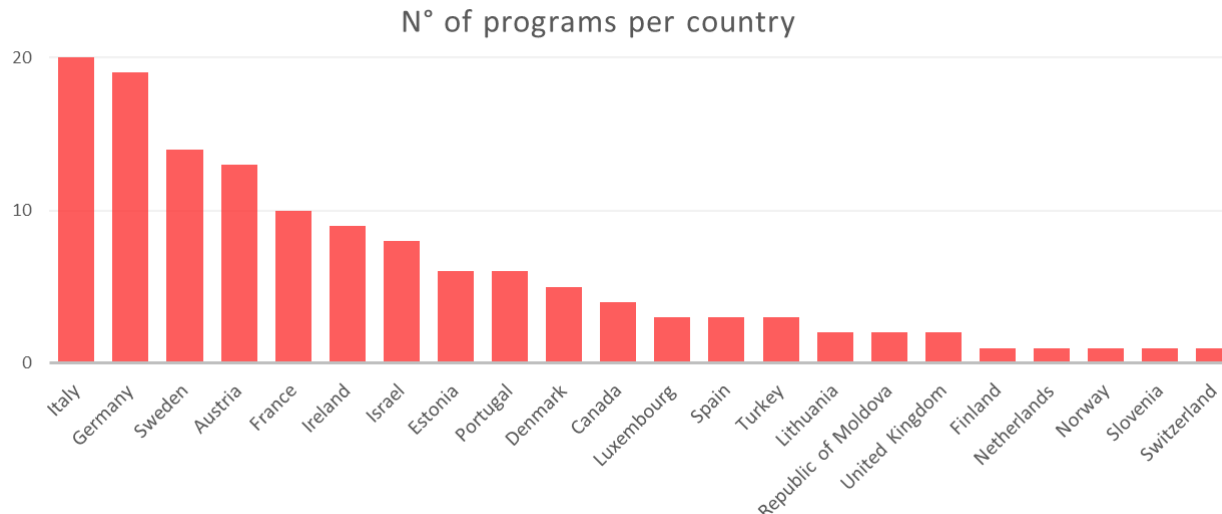
Personalised Medicine programs identified

N of total entries: 136

N of different programs: 97



Personalised Medicine programs identified/country



Events - 1st ICPerMed Workshop:

Innovative Concepts on Data Generation and Use for Personalised Medicine Research, Milan June 2017

- Experts participated by invitation
- Five interdisciplinary working panels on:
 1. Primary Prevention
 2. Disease Reclassification
 3. Impact of Data in Research
 4. Successful PM approaches
 5. New tools impact



www.icpermed.eu

Events - 1st ICPerMed Conference:

Personalised Medicine in Action, Berlin Nov 2018

- **Keynote talks**
- **Best practice sessions**
 - Research & Implementation: successful PM approaches
 - Policy: effective PM policy strategies and impact analyses
- ICPerMed **Mapping Database**
- ICPerMed **Best Practice Recognition**



ICPerMed Best Practice Recognition 2018

1. **NAGEN 1000: An example of a Project for Regional Implementation of Personalised Genomic Medicine in Healthcare** - Angel Alonso, Navarrabiomed, Spain
2. **Proposal of Recommendations for a National Strategy on Personalized Medicine Report** - Consuelo Martin de Dios, Fundación Instituto Roche, Spain
3. **In vivo evidence for ribavirin-induced mutagenesis of the hepatitis E virus genome**
- Daniel Todt, Twincore, Germany



ICPerMed Best Practice Recognition 2019

- **2nd Call** for Best Practice Examples in Personalised Medicine for **all citizens and patients within sustainable Health Systems**
- Evaluation ongoing

Events – 2nd ICPerMed Workshop

“Citizens, patients and implementation”



Instituto Nacional de Salud Carlos III Madrid
October 2019

Events – 2nd ICPerMed Conference

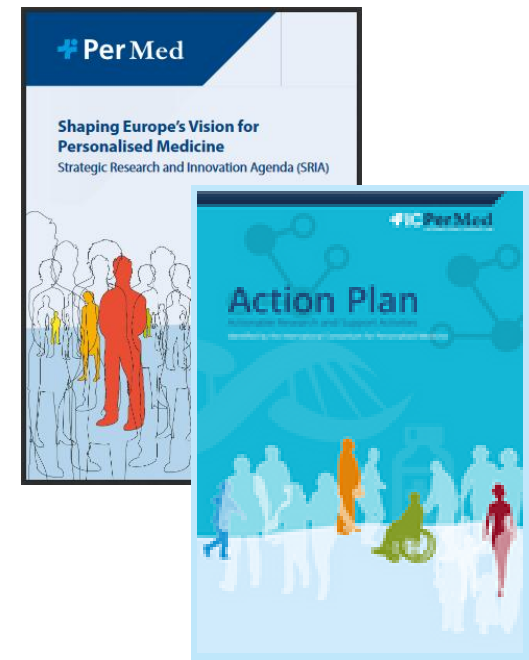
Paris 2020



ICPerMed is a growing Family...

ICPerMed and ERA PerMed

- **PerMed Strategic Research and Innovation Agenda**
recommended ERA-Net as funding instrument for PM research
- **ICPerMed Action Plan** - recommendations for topics of research in PM
- **ERA PerMed Consortium** was funded by the EC - November 2017
- Development and management of **Joint Transnational Calls by ERA PerMed** partners



ERA PerMed Consortium – 4 ERA-Net on PM topics

Coordination: Instituto de Salud Carlos III (ISCIII), SPAIN

1. Joint Transnational Call 2018:

Joint Call Secretariat: ISCIII, SPAIN



19 EU countries
 3 H2020 associated countries
 (Turkey, Norway, Israel)
 1 third country (Canada)

23 Countries

32 Funding org.

25 consortia funded, 25M€

<http://www.erapermed.eu/>




NEWSLETTER 1

January 2019

**ERA PerMed Results of the Cofunded
 Joint Translational Call 2018**

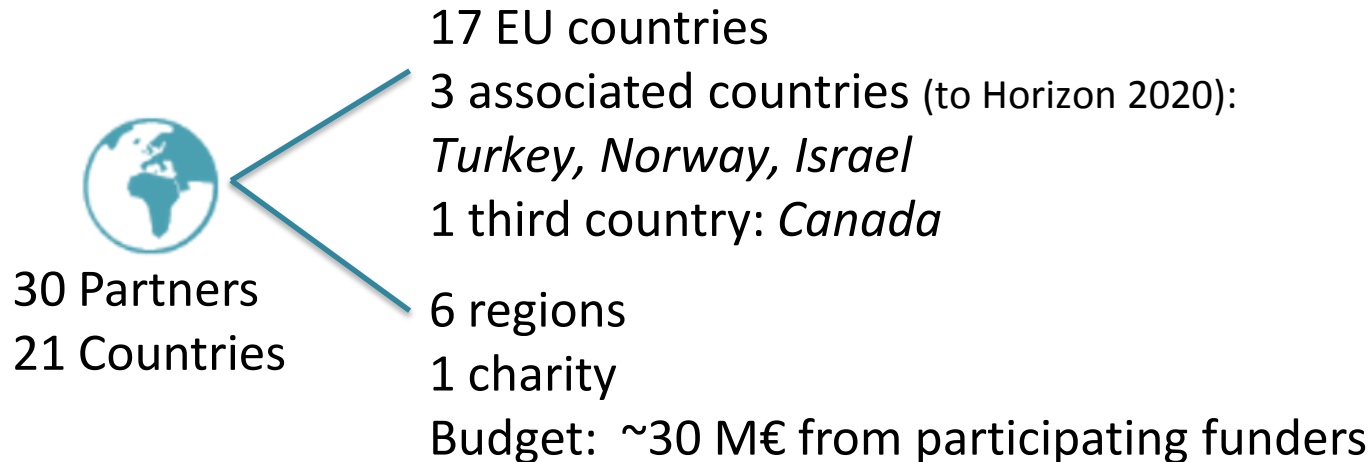
**“Research Projects on Personalised Medicine –
 Smart Combination of Pre-Clinical and Clinical
 Research with Data and ICT Solutions”**

25 Successful consortia are funded with a total
 investment of about 25 million Euro for three years

ERA PerMed Consortium – 4 ERA-Net on PM topics

2. Joint Transnational Call 2019:

Joint Call Secretariat: Agence National de la Recherche (ANR), FRANCE



A two step procedure

- Timeline:**
- Launch: 9th January 2019
 - Deadline for **Pre**-proposals: 7th March 2019
 - Deadline for invited **Full**-proposals: 17th June 2019
 - Expected start of granted projects: 2020

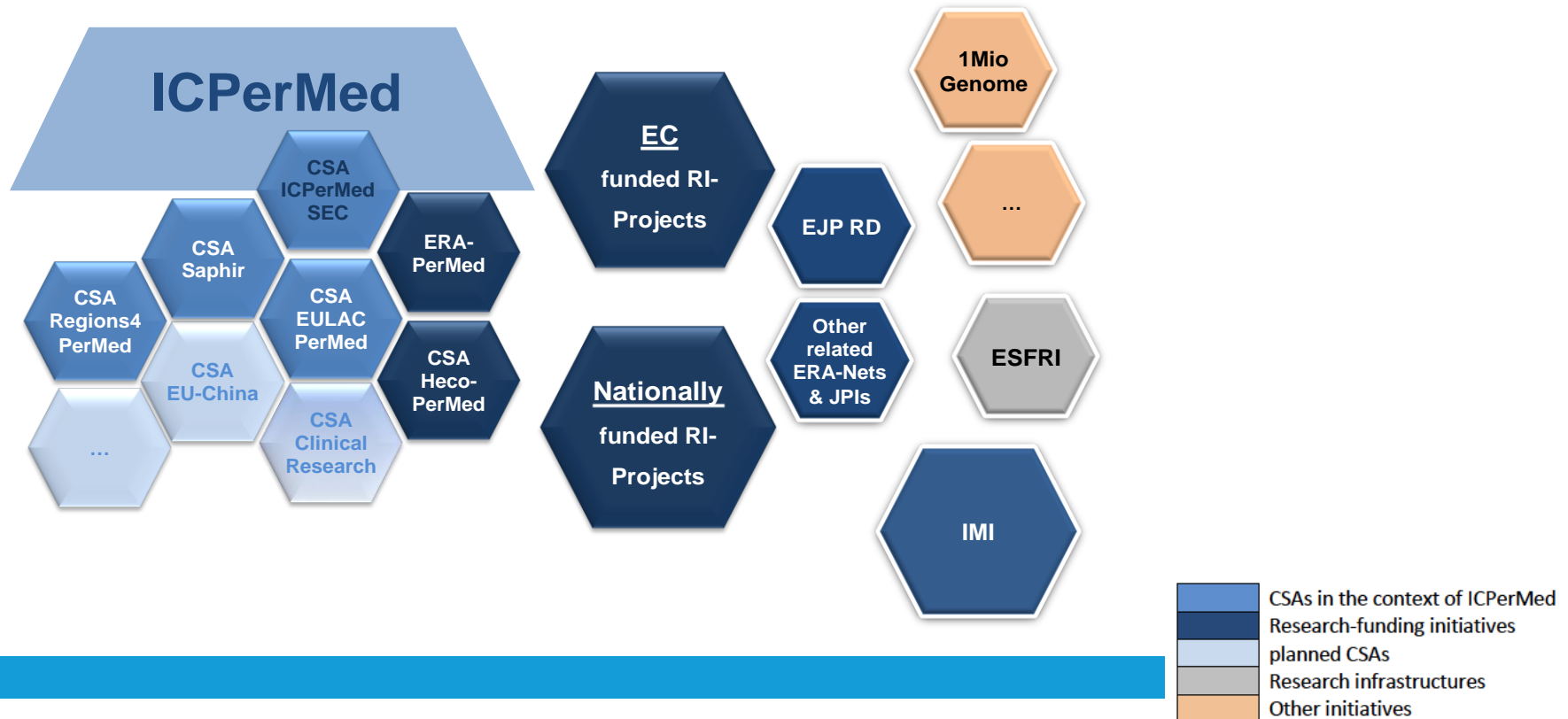
ICPerMed is a growing Family

Actions in support of ICPerMed - SC1-HCO-01-2018-2019 call
European Commission

- **4 new CSAs:**
 - **SAPHIRE** Securing adoption of personalised health in regions (European)
 - **REGIONS4PERMED** Interregional coordination for a fast and deep uptake of personalised health (European)
 - **EULAC-PerMed** Widening EU-CELAC policy and research cooperation in PM (Europe/Latin America and the Caribbean)
 - **HEcoPerMed** Health and pharma-economic modelling for supporting the ICPerMed (European)

ICPerMed is a growing Family

ICPerMed Family and related Initiatives



ICPerMed Newsletter

ICPerMed Statement concerning the 1 Million Genomes Declaration

On 10 April 2018, 18 Member States signed the Declaration (jointly signed by 1 Million Genomes in the European Union) by 2022, endorsed by the European Commission. ICPerMed has welcomed and supported the process of endorsing the declaration and has now issued a statement concerning the declaration.

ICPerMed stresses the importance of collaboration and coordination in the field of personalised medicine. Thanks to joint European and non-European efforts, personalised medicine is ready for citizens. ICPerMed strongly urges the coordination of activities in research and personalised medicine based on scientific European initiatives and infrastructures in the field.

Best practice sessions on research and implementation will give successful examples for translation of personalised medicine research into an added value for the patient. This will be done in a comparative approach giving room for representatives of all relevant areas, e.g. researchers, clinicians, doctors and patients. Further sessions will be organised as examples for policy making and impact analysis on personalised medicine research. These and practice sessions will be complemented by high-level key note talks on different aspects of personalised medicine. In addition, the winners of the ICPerMed Best Practice in Personalized Medicine Award will be announced and will present their results during a plenary session.

New ICPerMed Vice-Chair

ICPerMed is glad to announce that **Maribel O'Donoghue** from the National Health Research Science Board (NIHR) in Portugal has been elected Vice-Chair of the Executive Committee and will be further Vice-Chair of ICPerMed for the visible development of research.

ICPerMed Newsletter, June 2018

Outcome from IC PerMed Workshop Milan in June 2017

The first ICPerMed Workshop, organized by the Italian Ministry of Health and co-hosted by the Regional Foundation for Biomedical Research of Lombardy, took place in Milan from 26th to 27th June 2017. Aimed at identifying the state-of-the-art, the understanding and the new advances in the domain of personalised medicine by facilitating the exchange of experiences and ideas, the workshop was structured on three sessions covering the working panels: prevention in personalised medicine (PM), reclassification of genetic diseases, impact of data analysis in PM research, successful PM approaches and new tools in PM.

Progress has been made in establishing a shared cross-disciplinary language connecting the many fields that contribute to personalised medicine – including basic and clinical research, outcomes research, tool development, and market-oriented innovation.

During the ICPerMed Workshop, a number of areas that should be pursued with the highest priority to push the progress of PM were identified.

The outcomes of the Workshop will be published on the ICPerMed website and integrated in future recommendations, guidelines and vision papers.

ICPerMed Newsletter, November 2017

- Newsletters and a *Stakeholder Group* for staying connected with ICPerMed

Action Plan for Personalized Medicine published

ICPerMed recently published Action Plan for 22 research and 8 supporting activities, which have been identified as 'tasks for action'. These cover the whole healthcare value chain, from basic to clinical research and from diagnosis, and also take into account patient empowerment and sustainability of healthcare systems. ICPerMed requests the Action Plan as a blueprint for a long-term strategy for personalised medicine research and the reasonable implementation of resources and promising approaches in the health systems. Hence, it is the first time that such an impressive number of research findings and policy matters have been identified and published in a consensus view on the research and development needed in order to further advance personalised medicine.

ICPerMed provides a platform to initiate and support communication and exchange on personalised medicine research, funding and implementation. The high level of participation from all over Europe and beyond enables ICPerMed to efficiently map the scientific and political landscape. This allows an alignment of research and funding activities on European and even international level. Based on the solid knowledge of ongoing efforts, ICPerMed members will develop and agree on future research actions. In addition ICPerMed will identify the requirements for a suitable framework in terms of infrastructures, resources and regulatory procedures to foster the development and implementation of personalised medicine.

Thus, ICPerMed will contribute to the reasonable and far implementation of personalised medicine approaches into the health systems for the benefits of patients, citizens and society as a whole.

ICPerMed aims to provide a flexible framework for cooperation between member organizations. For that purpose, a so-called International Consortium model is used. According to this model, the member organizations use their own funding rules and policy processes to contribute to the overall goals and objectives of the consortium. Members include public and private non-for-profit health research funding and policy organizations. Although the current focus of the activities is on Europe, organizations from other parts of the world are also included already and hopefully more will join in the near future.

The member organizations of the International Consortium for Personalized Medicine will work to:

- Establish Europe as a global leader in personalized medicine research
- Support the personalized medicine science base through a coordinated approach to research
- Support research to investigate the benefits of personalized medicine to citizens and healthcare systems
- Pave the way for personalized medicine approaches for citizens

ICPerMed Newsletter, June 2017

www.icpermed.eu

More information about ICPerMed

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