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 ICPPerMed

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

Executive Committee
Members & Observers

Steering Board
Chair + 2 Vice-Chairs
Group Leads
Secretariat*
European Commission

Stakeholder Group

Secretariat*

Challenge Groups

Action Item Groups

*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

- **Data & ICT**
  - Integrating *Big Data & ICT* tools and infrastructure

- **Citizens and patients**
  - Innovation in diagnostics, therapies, prevention and ICT with economic value and fair access

- **Health systems**
  - Sustainable health systems

- **Market access**
  - Innovation transfer to the market

- **R&D**
  - Knowledge translation from basic research to clinical practice gap

- **PM awareness and patient engagement in health decisions**
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

• Mapping Activity: Ongoing funding programmes in PM
• Survey was sent to all ICPPerMed members
• Results are available in the ICPPerMed 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

![Bar chart showing the number of programs per country](image)
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

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

www.icpermed.eu
Events - 1st ICPereMed 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
- ICPereMed **Mapping Database**
- ICPereMed **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

• 2\textsuperscript{nd} Call for Best Practice Examples in Personalised Medicine for \textbf{all citizens and patients within sustainable Health Systems}

• Evaluation ongoing
Events – 2nd ICPPerMed Workshop

“Citizens, patients and implementation”

Instituto Nacional de Salud Carlos III Madrid
October 2019

Events – 2nd ICPPerMed 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

23 Countries
32 Funding org.

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

25 consortia funded, 25M€

http://www.erapermed.eu/
ERA PerMed Consortium – 4 ERA-Net on PM topics

2. Joint Transnational Call 2019:

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

- 17 EU countries
- 3 associated countries (to Horizon 2020): Turkey, Norway, Israel
- 1 third country: Canada

30 Partners
21 Countries

6 regions
1 charity
Budget: ~30 M€ from participating funders

A two step procedure
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


• 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

CSA Saphir
CSA Regions4 PerMed
CSA EU-China
CSA Clinical Research
CSA ICPerMed SEC
CSA EULAC PerMed
CSA Heco-PerMed

EC funded RI-Projects
EJP RD
Nationally funded RI-Projects
Other related ERA-Nets & JPIs
ESFRI
IMI

1Mio Genome

CSAs in the context of ICPerMed
Research-funding initiatives
planned CSAs
Research infrastructures
Other initiatives
ICPerMed Newsletter

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

www.icpermed.eu
More information about ICPPerMed

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