



# The International Consortium for Personalised Medicine

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# Personalised Medicine – A definition

*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

- Starting point for medical interventions should not be the disease but the patient, with his or her individual characteristics
- Have complete decoding of the human genome; rapid sequencing techniques; rapid processes for analysing biomaterials; ability to analyse large datasets
- Ineffective treatment / side effects - cost to patients and healthcare systems
- Existing diagnostic methods don't always provide clear results; delays cause a physical and psychological burden; allow the disease to progress

# Opportunities offered by PM

## For patients

- Targeted prevention of diseases: aim is to prevent or delay development of a disease.
- Early detection and treatment
- More precise diagnosis and more effective therapies; avoid trial and error approach to treatment; avoid unwanted side effects and ineffective treatments
- Develop new therapeutic procedures and products (still no effective treatment for many conditions)

# Opportunities offered by PM

## For healthcare system

- Concern about costs – two views:
  - Innovative or new treatments may cost more: e.g. more sophisticated diagnosis, production of drugs for small patient groups
  - But more specific diagnosis could lead to savings: avoid useless investigations, ineffective treatments. Shorten or even avoid periods of illness
- Better prevention and early detection on a broad scale should reduce costs

# Opportunities offered by PM

## For healthcare industry

Industry already aware of potential of PM; SME biotech companies in particular; partnering with pharma.

- Closing innovation gaps: difficulty of drug development and expiry of patents major challenges; need new approach.
- Reduction of R&D costs: stratify patient groups - carry out clinical studies with fewer test subjects. May speed up the process.
- Expanded use of approved drugs: more targeted use of approved drugs means their use can be expanded.

# Opportunities offered by PM

## For society

- More scope for personal decision making, esp. when it comes to detection of diseases and to selection of preventive and therapeutic procedures.
- More self-determination (but also an expectation that individuals take greater responsibility?)
- Use of personal data: how to balance the protection of personal data with the potential for using this data to save lives (needs input from humanities, law and social sciences)

# PerMed - a CSA

- Coordination and Support Action, financed by the European Commission (FP7)
- Title: “Personalized Medicine 2020 and beyond – Preparing Europe for leading the global way”
- Aim: Dialogue platform; strategic research and innovation agenda
- Duration: 24 months (2013 – 2015)
- Budget: 500,000 Euro
- 27 partners from 14 countries



# PerMed - Objectives

- Step up coordination efforts between European key stakeholders
- Allow synergies and avoid duplication or competition
- Ensure maximum transparency and openness
- Identify and discuss gaps & needs with stakeholders
- Identify promising research topics and developments
- **Make strategic recommendations on how to foster the implementation of Personalised Medicine**

# 18 partners and 9 cooperating partners

- Research and Health Ministries,
- Funding Bodies
- Research Institutes, Industry, SMEs, Foundations and Societies
- Connected to other European initiatives

(e.g. EuroBioForum, ESF, EAPM, CASyM, 3GBTest and EPEMED)



# SRIA – 35 Recommendations in 5 Challenges

## Challenges

- 1 – Developing Awareness and Empowerment
- 2 – Integrating Big Data and ICT Solutions
- 3 – Translating Basic to Clinical Research and Beyond
- 4 – Bringing Innovation to the Market
- 5 – Shaping Sustainable Healthcare

## Research areas

- A) Biomedical, health-related ICT and health research
- B) Humanities and social sciences research
- C) Improvement of the framework for implementing PM

# ICPerMed - Background

## Timeline:

- Building on PerMed (2013-2015)
- Several workshops organised by the European Commission
- Conference on Personalised Medicine in June 2016
- Official launch: November 2016

# ICPerMed – an international consortium

Aim: to bring funders, ministries and EC together to coordinate and foster **research** in personalised medicine

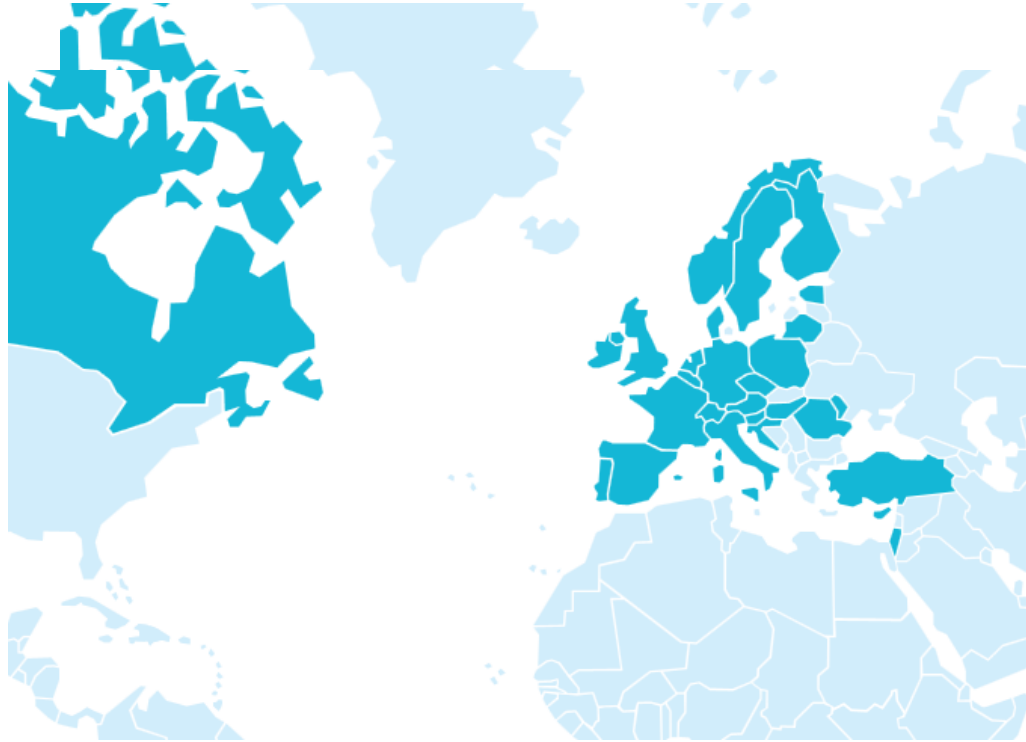
- Over 30 European and international partners
- Representing ministries, funding agencies and the European Commission (EC)
- International consortium model (similar to IRDiRC or IHEC)

# ICPerMed Vision Statement:

## Research as driver of personalised medicine

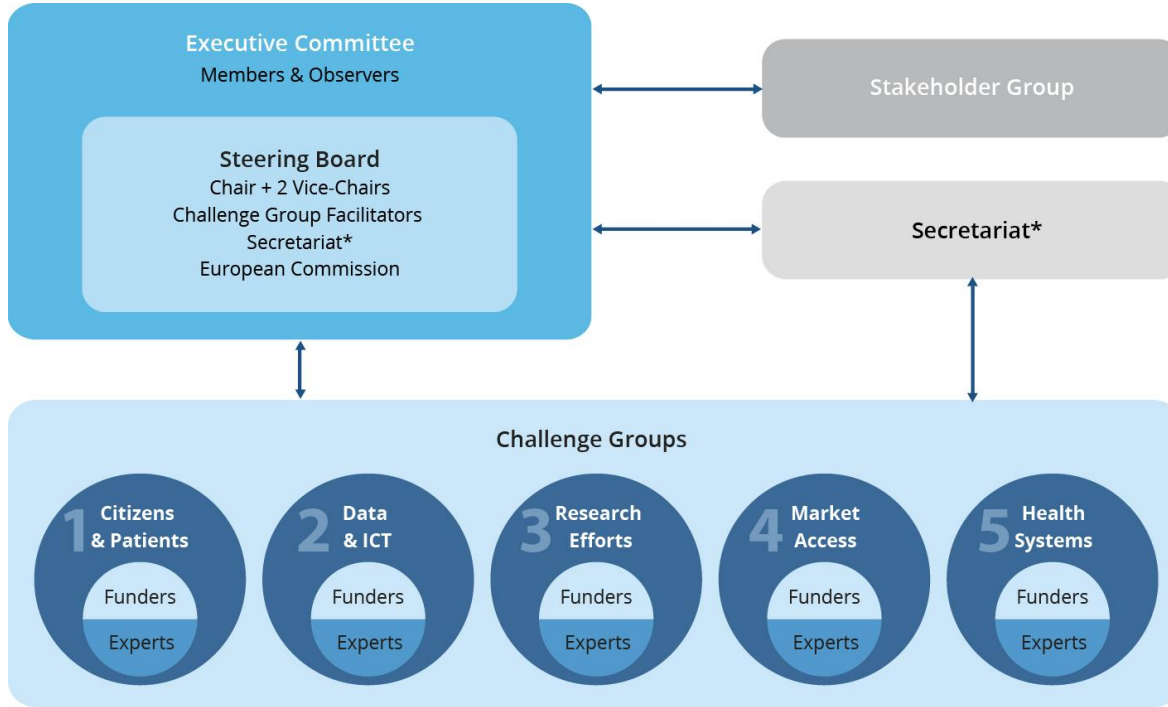
- Establish **Europe as a global leader** in personalised medicine research.
- Support the **personalised medicine science base** through a coordinated approach to **research**.
- Support research to investigate **the benefits** of personalised medicine to **citizens** and **healthcare systems**.
- Pave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

## Members of ICPerMed



- 30 funding bodies from EU member states and beyond
- Public and private 'not for profit' health research funding and policy organisations

# ICPerMed Governance

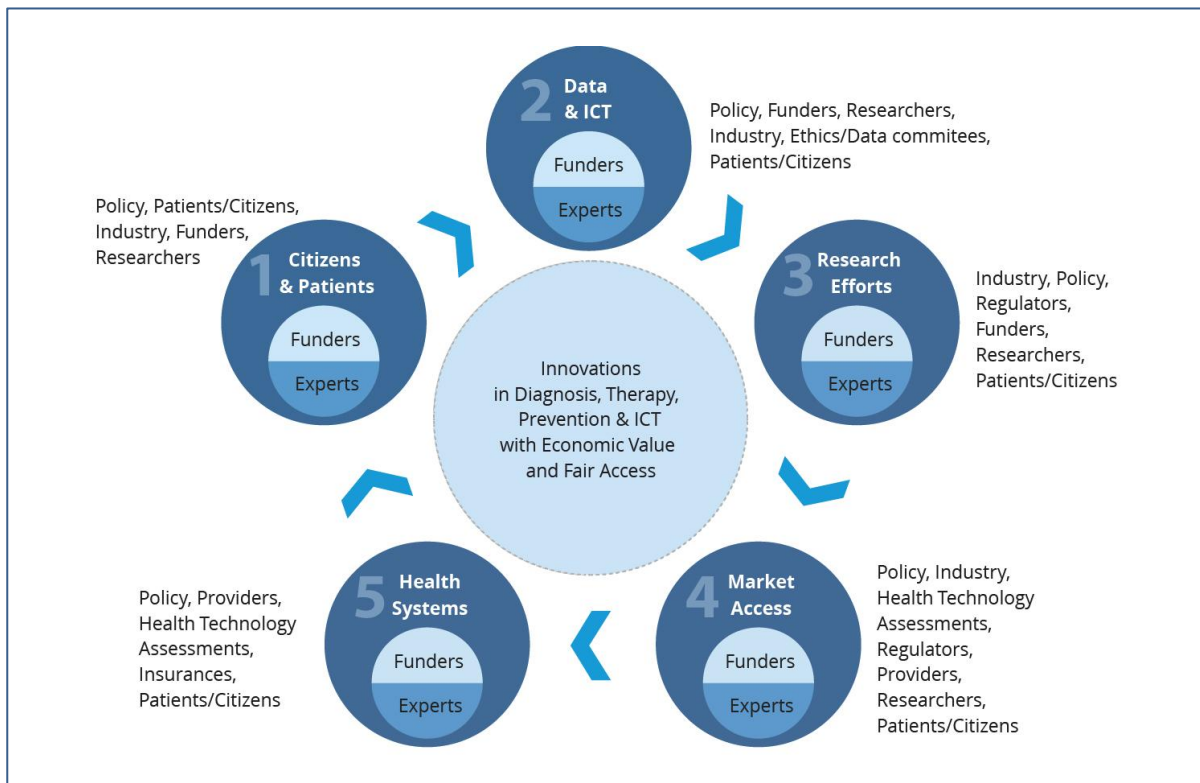


\* The Secretariat is a Coordination and Support action funded by the European Union's Horizon 2020 research and innovation programme under grant agreement no. 731366.





# ICPerMed Challenge Groups



Whole healthcare value chain and beyond

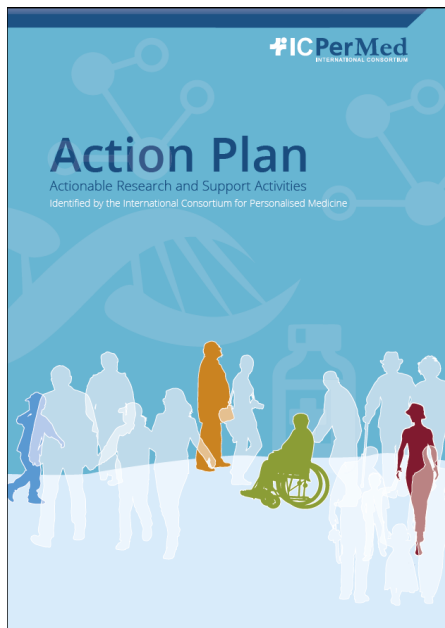
1. Citizens and Patients
2. Data & ICT
3. Research Efforts
4. Market Access
5. Health Systems

**Funders & Experts**

# ICPerMed – Development of the Action Plan



# ICPerMed Action Plan



- 22 Actionable Research and 8 support activities
- Will feed into national and European strategic discussion of research funders

Released in March 2017

# Action Plan – Data

## A.1 – A.8 Research

- Quality, harmonisation, integration of data
- Structured data from unstructured sources
- Data sharing
- Data security, privacy and ownership
- Telehealth and Telemedicine

## B.1 Support – Structures

- High-quality, sustainable databases

# Action Plan – Technologies, Methods and Processes

## A.9 – A.18 Research

- Preclinical models, translation, clinical trials, longitudinal cohort studies
- Health economics and pharmaeconomics
- Classification of diseases at molecular level
- Regulatory structures
- surveillance methods

# Action Plan – Technologies, Methods and Processes

## B.2 – B.6 Support

- Biobanks; population and disease cohorts
- New funding models, integrating health care providers
- New research and technology transfer strategies
- Financial and risk-sharing instruments
- Optimisation of health systems for implementation of PM

# Action Plan – People

## A.19 – A.22 – Research

- Health and digital literacy
- Instruments for public engagement
- Ethical, legal and societal perspectives\*

## B.7 – B.8 Support

- Health system sciences in education of healthcare professionals; e.g. health system sciences
- Sustainable resources for educating citizens and patients on involvement of patients

\* cross-cutting activity

## Next steps for ICPerMed

- Developing work programme to implement the Action Plan
- ERA-Net Cofund in personalised medicine (ERA PerMed) – first call for proposals 2018 (up to 3 more calls)
- Database of EU wide personalised medicine activities (to inform funding priorities, funding strategies, policies) + partnering tool
- Mapping project – PM related initiatives
- Series of workshops and conferences over next four years



# How to get involved

- ICPerMed Partnering Tool: search for partners and present your expertise to the personalised medicine research community
- ERA-Net in personalised medicine research: first call for proposals to be published in 2018
- Sign up for alerts

More information about ICPerMed:

[ICPerMed@dlr.de](mailto:ICPerMed@dlr.de)

[www.icpermed.eu](http://www.icpermed.eu).