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:
  o Innovative or new treatments may cost more: e.g. more sophisticated diagnosis, production of drugs for small patient groups
  o 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 ICPePerMed

- 30 funding bodies from EU member states and beyond
- Public and private ‘not for profit’ health research funding and policy organisations
ICPerMed Governance

Executive Committee
Members & Observers

Steering Board
Chair + 2 Vice-Chairs
Challenge Group Facilitators
Secretariat
European Commission

Stakeholder Group

Secretariat*

Challenge Groups

1. Citizens & Patients
   Funders
   Experts

2. Data & ICT
   Funders
   Experts

3. Research Efforts
   Funders
   Experts

4. Market Access
   Funders
   Experts

5. Health Systems
   Funders
   Experts

* 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

1. PerMed
   Strategic Research & Innovation Agenda

2. Challenge Groups
   Funders & Experts


4. Executive Committee
   Funders

5. ICPPerMed Action Plan
   Actionable research items
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 ICPPerMed

• 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

• ICPPerMed 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 ICPPerMed:

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