

The International Consortium for Personalised Medicine

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ICPerMed – an international consortium

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

Aim: to coordinate and foster **research** to develop and evaluate personalised medicine approaches

ICPerMed Vision Statement:

- 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**

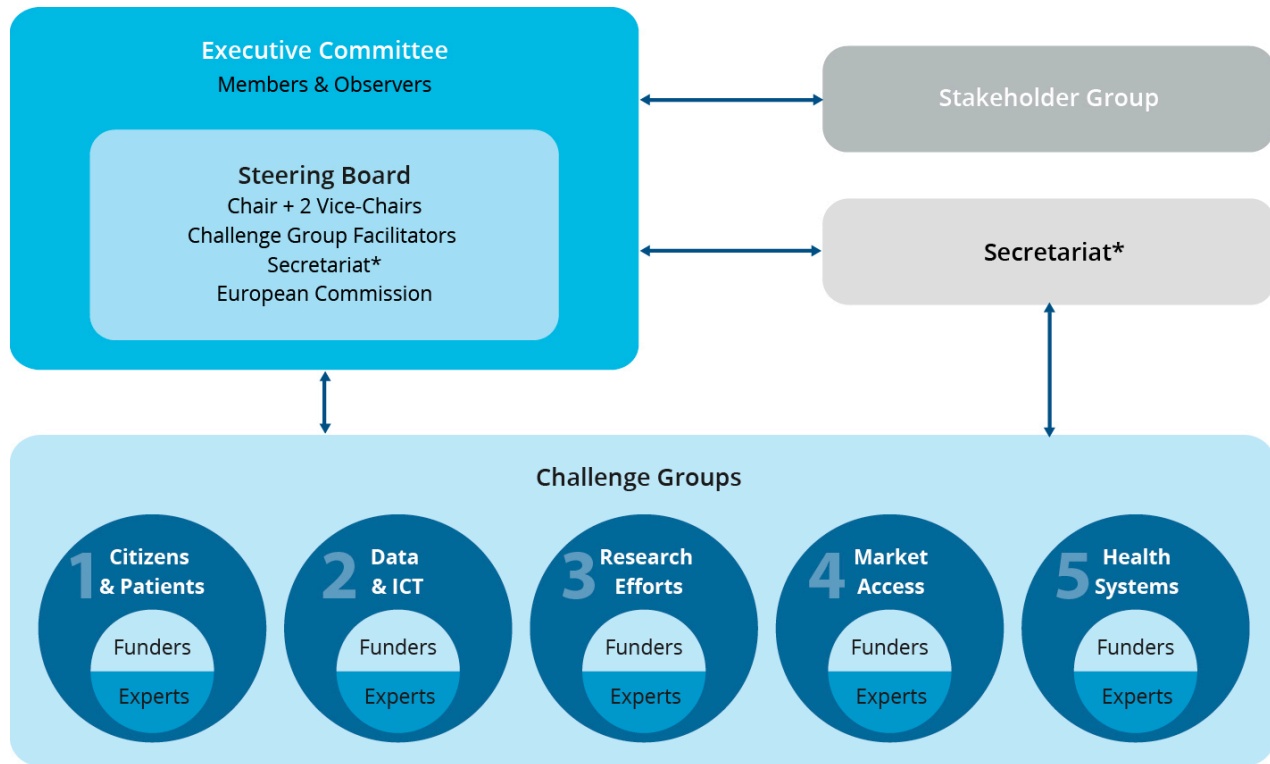
Research as driver of personalised medicine

Personalised Medicine – definition

*“refers to a medical model using
 Characterisation of individuals’ phenotypes and genotypes
 (e.g. **molecular profiling, clinical symptoms, 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)

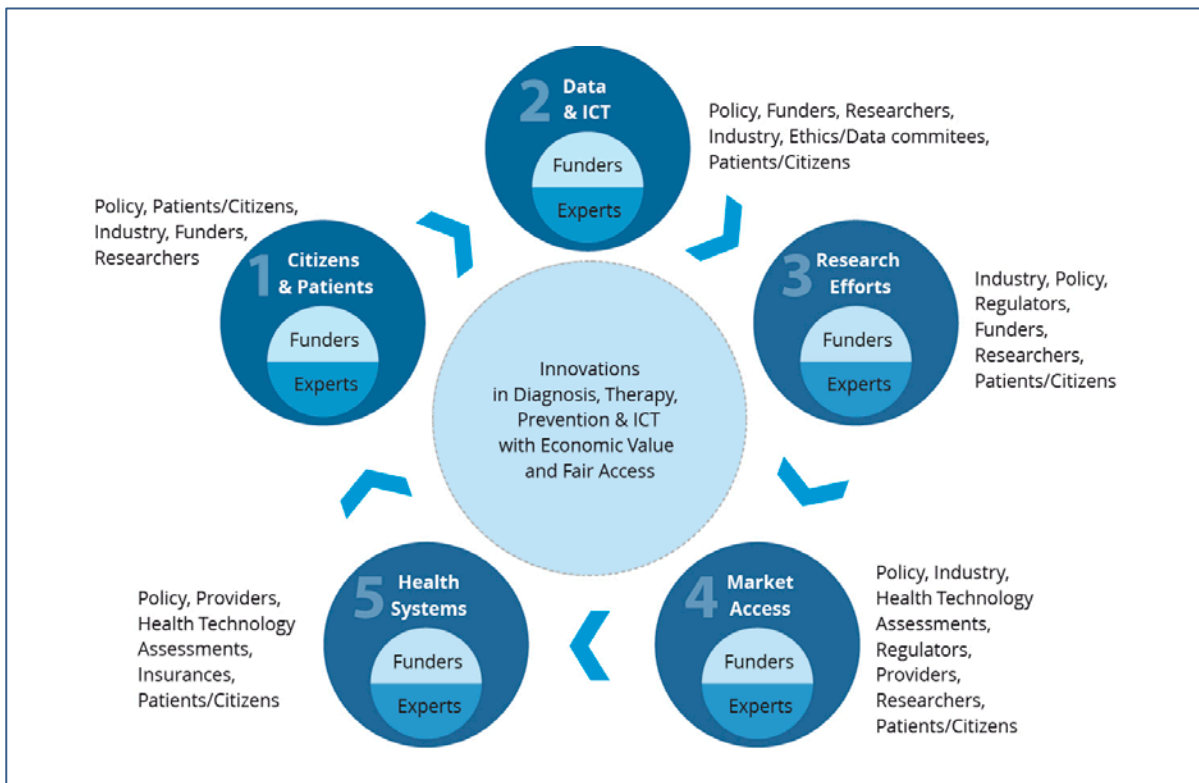
ICPerMed Governance



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ICPerMed Challenge Groups



Whole healthcare value chain and beyond

1. Citizens and Patients

2. Data & ICT

3. Research Efforts

4. Market Access

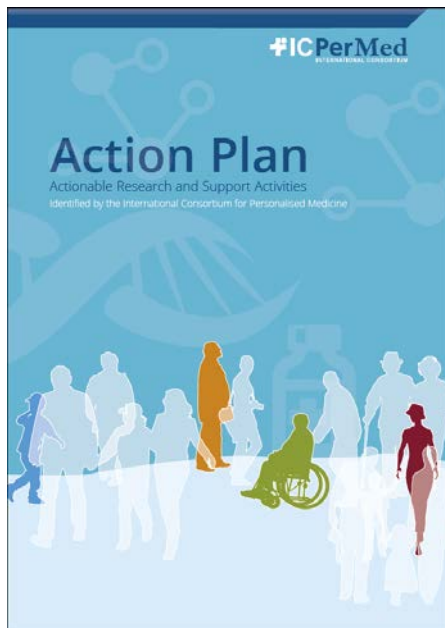
5. Health Systems

Funders & Experts

ICPerMed – Development of Action Plan



ICPerMed Action Plan



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

To be released in March 2017



Challenge Group 1 scope

*To enhance the involvement of patients and healthcare professionals **in trainings** in order*

- *to have access to accurate health information*
- *person-centered services,*
- *to take informed decisions,*
- *to interact with researchers*

Interdisciplinary research to identify and pilot the best concepts for education and training of healthcare professionals and patients



From passengers to co-pilots: Patient roles expand

„If patient engagement were a drug, it would be the blockbuster drug of the century and malpractice not to use it“

Leonard Kish 2012

Patients have been the passive recipients of medical care with little role in research.

Even as research subjects, patients were not required to give informed consent prior to adoption of the Nuremberg Code in 1947.

Patient participation has expanded dramatically.

Opportunities abound to serve as active partners in defining and prioritizing research questions and solutions.





The main areas influencing the future of healthcare in PM

Change the medical model, create a new model for care with patients

- **Cultural changes**: patient centric vs. physician centric model, moving to value based delivery model
- Improve the patients **health literacy**: enhance informed decisions –share the responsibility, motivate the person for healthier living
- **Reform education** of healthcare professionals

Leveraging Technology to Enhance Patient Engagement

- New type of **communications** (ePatients, social media, internet based self pre-primary care, patients groups)
- IT driven **health monitoring** (e-Health, mHealth, homeCare, eHRs)

Paradigm change in the science

- Patient science – DIY biology, genetics, biotechnology
- **Patient centric clinical trials**





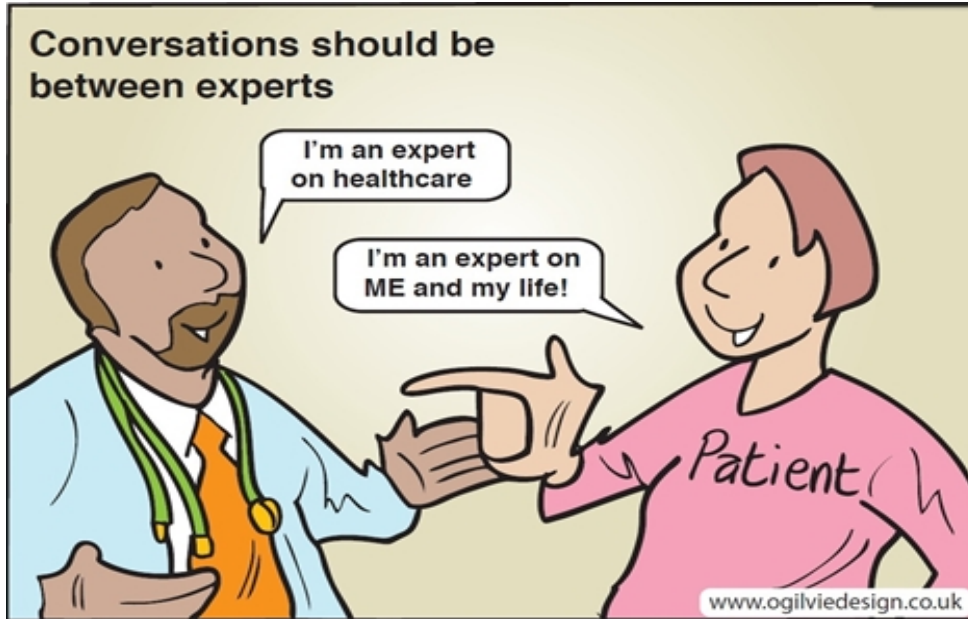
Leveraging Technology to Enhance Patient Engagement

Engaged Patients → Value based healthcare

- Enhancements in patient engagement lead to **better outcomes**, eg. **improving medication adherence** would have a positive **impact on patient outcomes and healthcare costs**
- Patient experience and patient satisfaction are more intertwined than ever

Smart Technology Leverage Can Yield Rapid Impact

- **Modern tools to efficiently manage communications**, monitoring and care plan interactions between patients and their care team.
- **Rules-based process automation tools** to intelligently manage self-service interactions with patients – to optimize their care, as well as improve clinical staff utilization.
- **Embedded analytics** to drive continuous improvement of varying program elements within the many patient sub-groups who respond differently to varied approaches.



Barriers of Engagement

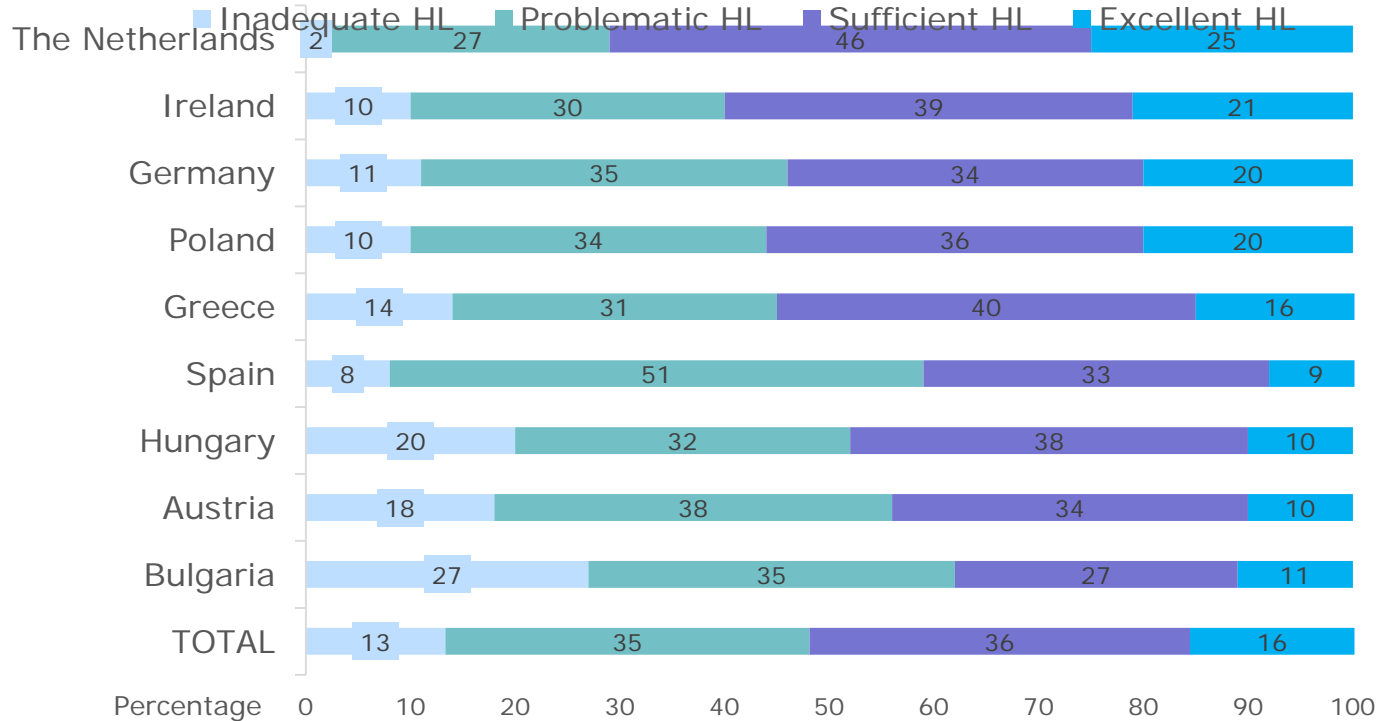
System Barriers

- Culture
- Infrastructure
- Financing

Patient Barriers

- Activation
- Literacy
- Diversity
- Unpredictability
- Financing

Levels of general health literacy (HL) index by country and for the total sample



Source: Health Literacy Survey EU 2015, <http://eurpub.oxfordjournals.org/>

Action plan items of Challenge Group 1.



Identify and develop the tools and modus operandi of a knowledge network for enhancing health and digital literacy, and build networks (eg.web-based and/or social media, network of patient's academies)



Identify and develop the instruments and evaluate the effectiveness, contribution and impact of public engagement initiatives in personalised medicine (mHealth, data sharing, leveraging technologies)



Develop and share best practices (standardisation, harmonisation as well) on a range of patient engagement approaches in order to meet the needs of a variety of patients, and the European population

Supporting activities



Introduce curricula reforms in universities at graduate and post-graduate level for healthcare providers to create new models of healthcare

Broaden the focus on basic and clinical sciences to include health systems sciences in the education of all healthcare professionals



Build sustainable resources for educating and training citizens, patients and patient advocates on involvement of patients and patient organizations across the entire research & development lifecycle of personalised medicine

Thank you!

More information about ICPerMed:

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