

# The International Consortium for Personalised Medicine

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**European Medicines Agency (EMA) Patients' and Consumers'(PCWP) and Healthcare Professionals' (HCPWP) Working Parties joint meeting  
March 2-3, 2021**



# ICPerMed – An International Consortium

- Coordination & Support Action, funded by the European Commission to promote personalised medicine
- Started in 2016 and will continue until 2023 and beyond
- Almost 50 European and international partners
- Members include public and private `not-for-profit` health research funding and policy organisations and the European Commission

Overall aim: To coordinate and promote **research** along the full value chain to develop and evaluate personalised medicine approaches

## ICPerMed Vision Statement:

- Establish **ICPerMed members as global leaders** 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**

# ICPerMed Actions:



**Events & publications**

**Tools & communications**



ICPerMed Workshop 2017  
**Innovative Concepts on Data Generation  
and use for Personalised Medicine Research**  
Milan, June 26-27, 2017

ICPerMed Conference 2018  
**Personalised Medicine in Action**  
Berlin, November 20-21, 2018




ICPerMed Workshop 2019  
**Personalised Medicine for All Citizens and  
Patients within Sustainable Implementation**  
Madrid, November 5-6, 2019

ICPerMed Conference 2021  
**Personalised Medicine –  
From Vision to Practice**  
virtual, February 25-26, 2021







# ICPerMed Conference 2021: Personalised Medicine – From Vision to Practice February 25-26, 2021



## Objectives

- During the conference, ICPerMed will be committed to demonstrate the importance and the need to address personalised medicine challenges about **patient preferences, data harmonisation, personalised medicine implementation into healthcare systems, collaboration between academia and industry and, finally, on health economics aspects.**
- A session on “The challenges to a Personalised Medicine Approach for infectious diseases – Lessons learned from the COVID-19 pandemic” will be dedicated to the **COVID-19 pandemic and how personalised medicine approaches could be part of the solutions.**
- Furthermore, ICPerMed will feature and honour during the event best practices in personalised medicine research through the **ICPerMed Recognition 2020**, aiming to recognise, encourage, promote and disseminate outstanding examples.

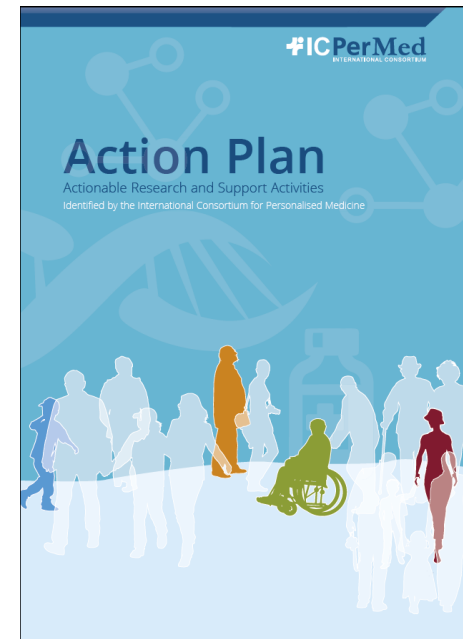
# ICPerMed Action Plan: Mapping the permed landscape

## A) Research activities:

- Data
- Technologies, Methods and Processes
- People
- Cross-Cutting

## B) Support activities:

- Structures
- Methods and Processes
- People



# Development of the ICPerMed Action Plan



- Actionable research and support activities
- Input to national and European strategic discussion of research funders

Released in March 2017

Progressed followed by 5 Action Item Groups

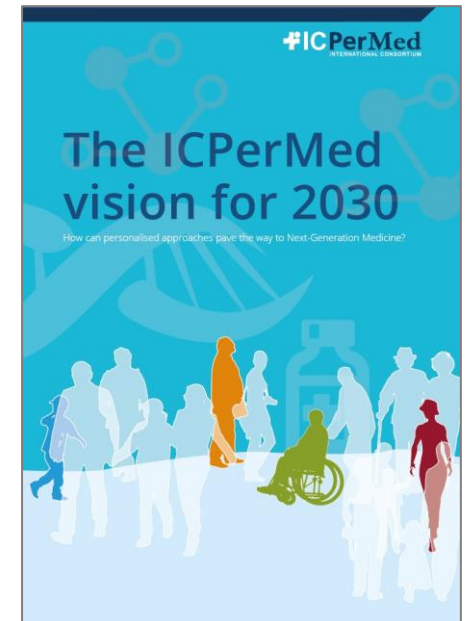


# ICPerMed Vision Paper

- Future vision of ICPerMed on personalised medicine research and implementation by 2030:

**“How can personalised approaches pave the way to next-generation medicine?”**

- Based on consultation of European and international experts, covering the entire range of relevant sectors and professional backgrounds
- Available for download on the ICPerMed website: <https://www.icpermed.eu/en/activities-vision-paper.php>



# Personalised medicine is developing rapidly!

## Genomic Medicine Sweden

The Genomic Medicine Sweden (GMS) initiative aims to contribute to personalised medicine and improved healthcare across Sweden. This will be accomplished through the implementation of large-scale sequencing techniques within healthcare. As new technologies mature, the aim is also to include other omics technologies to provide next-generation diagnostics in healthcare.

## Pharmacogenetic Recommendations for Personalised Medicine

In this study published in [Genetics in Medicine](#), a team of geneticists and bioinformaticians around Dr. Lili Milani at the University of Tartu developed and tested algorithms for translation of preexisting genotype data of over 44,000 participants of the Estonian biobank into pharmacogenetic recommendations.

## Personalised medicine in action: How the adoption of electronic medical records (EMR) is supporting a personalised "taking care" approach and the development of predictive algorithms

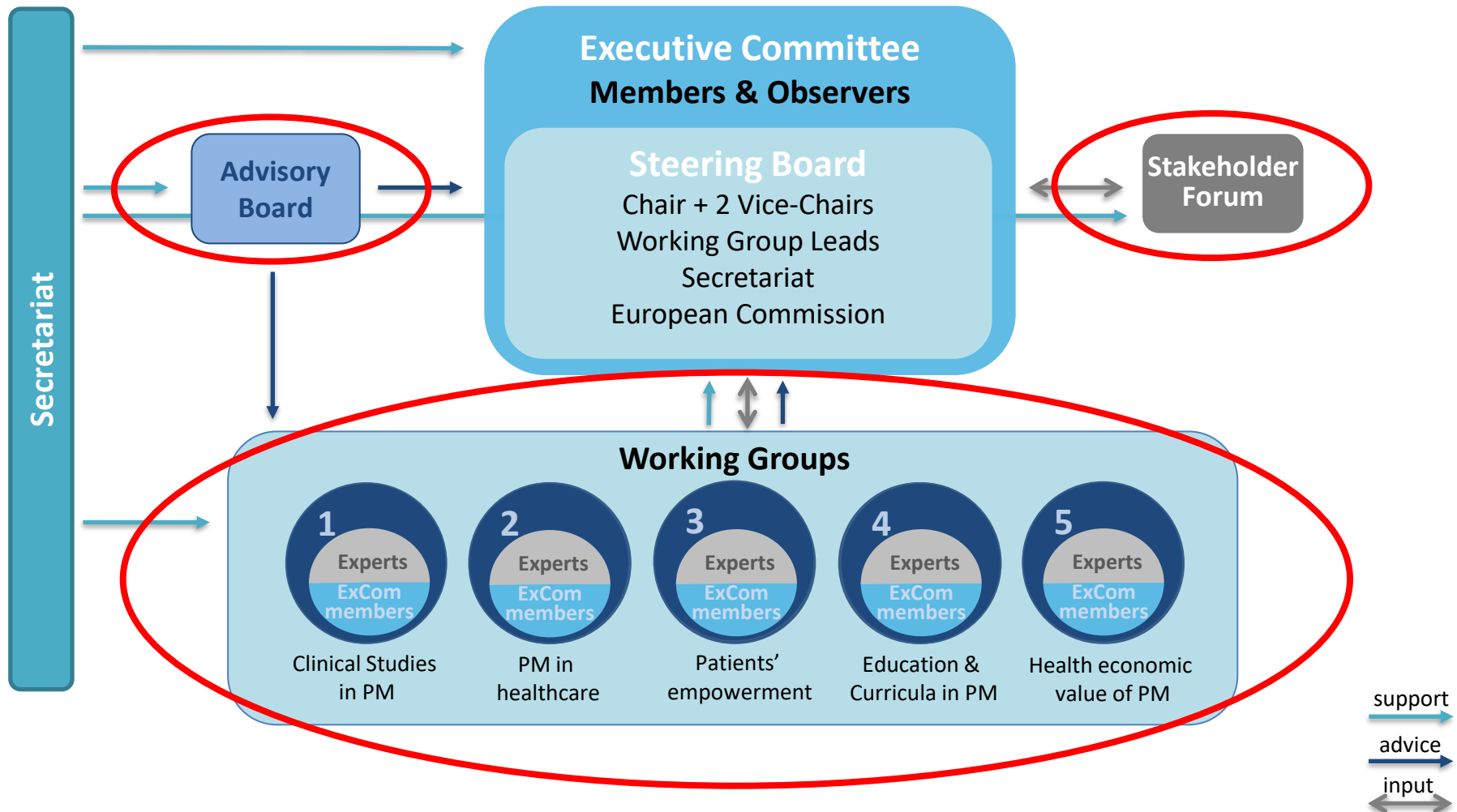
Since the early 2000's the hospital of Vimercate, a town of approx. 25,000 inhabitants close to Milan, has implemented the Electronic Medical Records (EMR). The application of EMR was triggered by three major needs:

**Genomic medicine** is profoundly changing patient care. Routine genome sequencing will enable a high number of patients to benefit from more personalised diagnostics and **personalised therapeutic care**. This includes rare diseases and cancer but also more common diseases (e.g. metabolic, cardiovascular, neurological diseases).



From early research towards implementation in healthcare

# ICPerMed Governance revised in Oct 2020



# Continued overall focus on full value chain as outlined in Action Plan

## New working groups for the next three years:

- Clinical Studies in PM
- PM in healthcare
- Patients' empowerment
- Education & Curricula in PM
- Health economic value of PM

### EMA regulatory science in 2025

- Catalysing the integration of science and technology in medicines development
- Driving collaborative evidence generation improving the scientific quality of evaluations
- Advancing patient-centred access to medicines in partnership with healthcare systems
- Addressing emerging health threats and availability/therapeutic challenges
- Enabling and leveraging research and innovation in regulatory science

**Members:** ICPerMed members & selected external experts

**Aim:** Implement the ICPerMed activities prioritised by the Executive Committee

- Collect and present best-practice examples
- Develop recommendations and guidelines
- Develop and contribute to white papers of ICPerMed

# Stakeholder Forum

## **The ICPerMed Stakeholder Forum strives to achieve the following:**

- sharing of ideas and best practice examples
- identification of emerging issues and research fields
- establishment of new communication channels & effective dissemination avenues
- foster new partnerships & networks

## **Members of the Stakeholder Forum will:**

- receive up-to-date information on ICPerMed activities and output,
- be invited to ICPerMed events like workshops or conferences
- be given the opportunity to share personalised medicine-related information to an expert audience
- be asked to provide their perspective to specific issues and provide advice / opinions / comments on ICPerMed strategic documents



# Stakeholder Forum

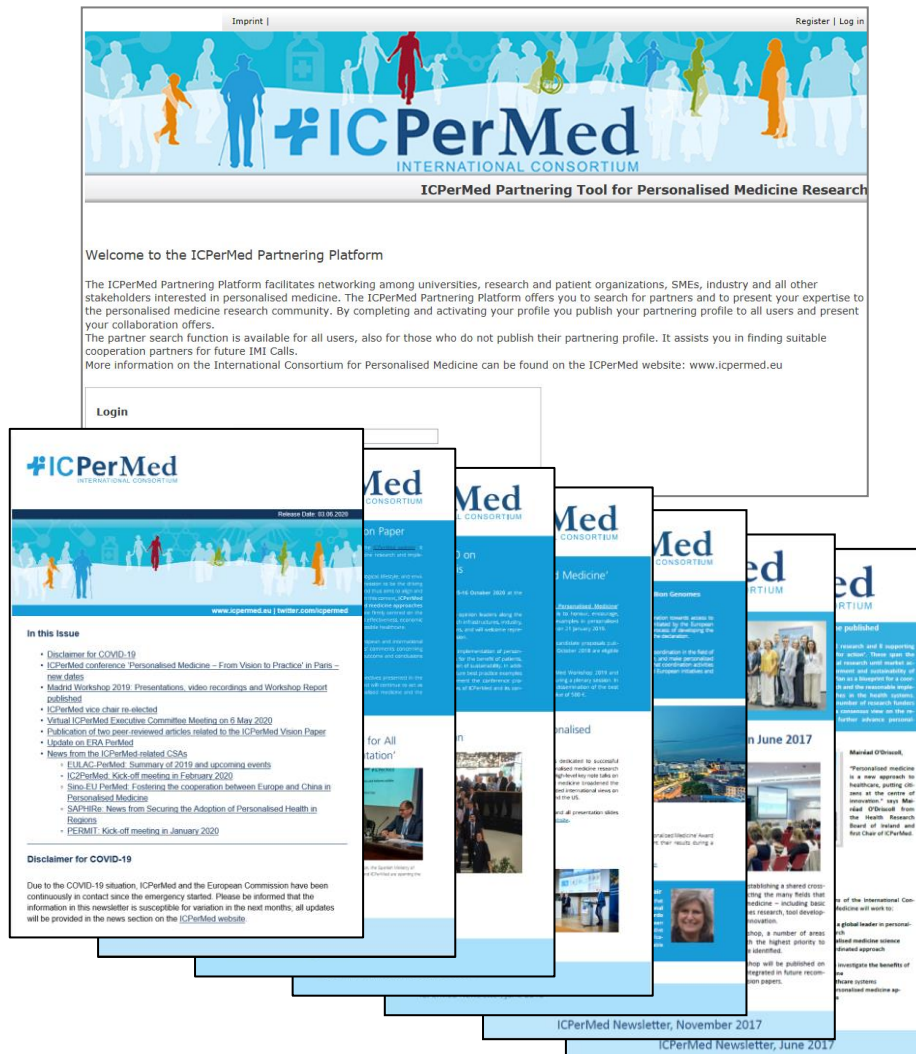
If you are interested to become an ICPerMed Stakeholder, please join the Stakeholder Forum here:

<https://www.icpermed.eu/en/services-stakeholder-forum.php>

- Stakeholders are generally expected to join by **self-nomination**. After self-nomination, approval of the ICPerMed Steering Board is required.
- Membership status of the Stakeholder Forum will be **revised annually** by Steering Board

# Partnering Tool & Newsletter

- Platform for research organisations to find potential cooperation partners
- Was used e.g. by ERA PerMed and Flagship Canada/EU call
- More than 980 entries so far
- Newsletter for staying connected with ICPerMed
- registration on ICPerMed website: <https://www.icpermed.eu/en/services-newsletter.php>
- Twitter account: @ICPermed



# Funder's Survey and Database



**ICPerMed**  
INTERNATIONAL CONSORTIUM

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

E-Mail:

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 Login

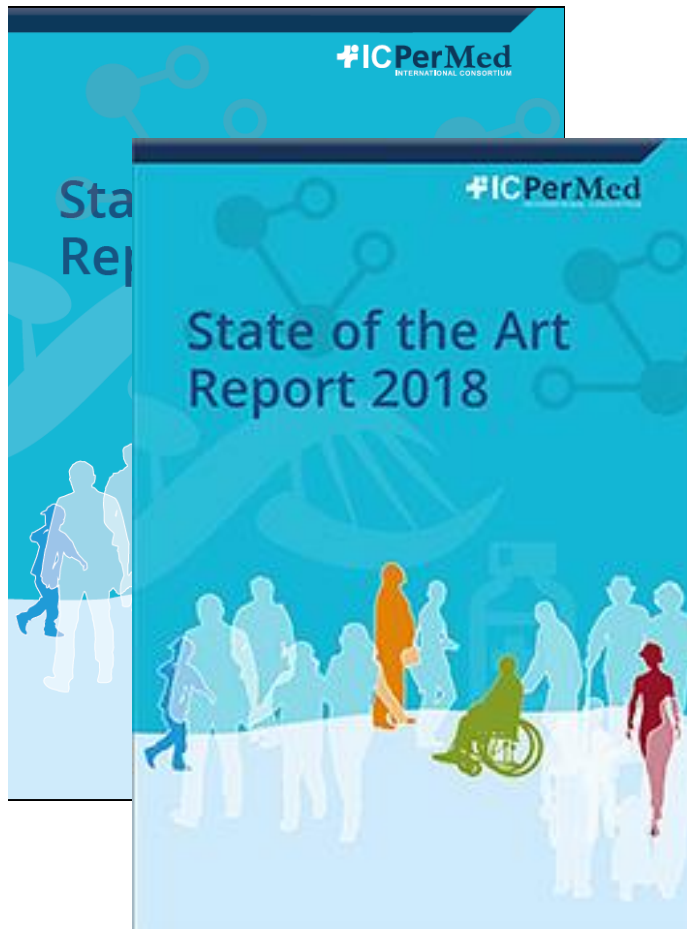
[Forgot your password? Register](#)

- Mapping Activity: Ongoing funding programmes in Personalised Medicine
- Survey sent to all ICPerMed members
- Results are available in the ICPerMed mapping database
- open to the public after simple registration

As of February 2021:

- 284 registered users

# ICPerMed State of the Art Report

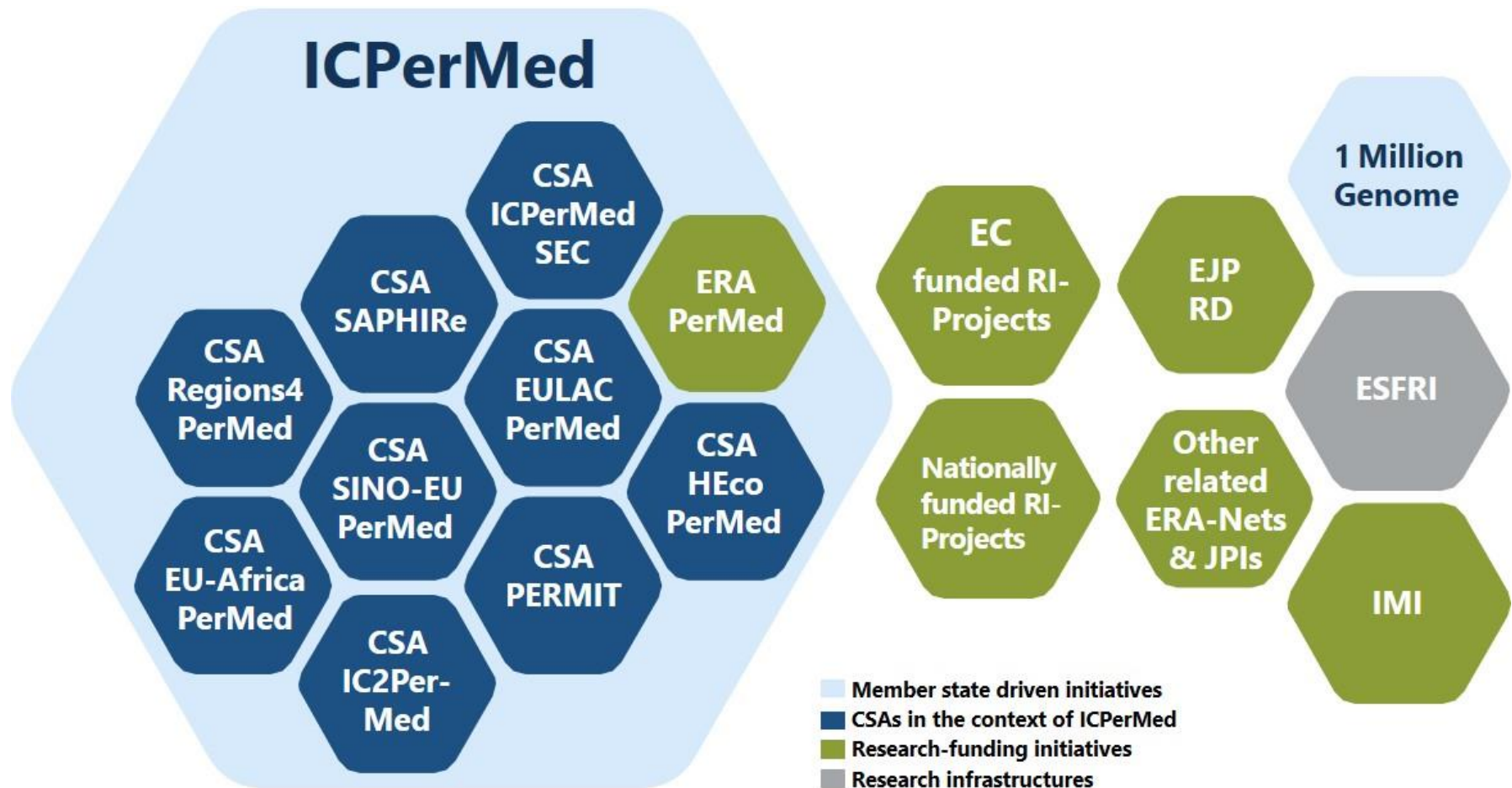


- Available on ICPerMed Website
- First year: Mainly report on ICPerMed Activities
- Second year: Analysis of funding activities in personalised medicine, best practices
- Future reports: More general overview over the field of personalised medicine

Released June 2018 and November 2019

State of the Art Report jointly for 2019 & 2020 to be published soon

# ICPerMed „Family“ and related initiatives





# European Partnership on Personalised Medicine (EP PerMed)

- One of the new partnerships under the Horizon Europe framework is proposed to be dedicated to personalised medicine (EP PerMed)
- As a consequence, representatives from ICPerMed and ERA PerMed prepared a draft concept paper describing how EP PerMed could look based on the two organisations's experiences from the last five years
- This concept paper is now available and will be used by the European Commission in the upcoming Member States consultations

<https://www.icpermed.eu/en/draft-concept-paper-european-partnership-for-personalised-medicine-777.php>

<https://erapermed.isciii.es/draft-concept-paper-european-partnership-for-personalised-medicine-ep-permed/>

- Please take a look at this document – we need support from all of you to ensure that EP PerMed becomes reality

# Thanks for your attention

## Questions?

More information about ICPerMed:

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

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

