ICPerMed
INTERNATIONAL CONSORTIUM

Workshop Report

Second ICPerMed Workshop

Personalised Medicine for all Citizens and Patients within Sustainable Implementation

5-6th November, 2019
Madrid, Spain

Imprint

EU grant

The Coordination and Support Action (CSA) ICPerMed Secretariat has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 731366.

Authors
The ICPerMed Secretariat, represented by the National Institute of Health Carlos III (ISCIII) (Cristina Nieto Garcia and Marina Moreno Llanos)

Supported by Candida Sanchez Barco, on behalf of the International Consortium for Personalised Medicine, ICPerMed.

Acknowledgement
ICPerMed would like to thank all experts who supported ICPerMed by their valuable input via the ICPerMed workshop in Madrid (November 2019).

Contact
National Institute of Health Carlos III (ISCIII)
ICPerMed@isciii.es

ICPerMed Secretariat
Dr. Ulrike Bußhoff
E-mail: ICPerMed@dlr.de
ICPerMed webpage: http://www.icpermed.eu

Publisher
Deutsches Zentrum für Luft- und Raumfahrt e. V. (DLR) / DLR Project Management Agency, Department Health
Linder Höhe, 51147 Cologne, Germany

Date
May 2020

Design and layout:
DLR Project Management Agency

Content

I- Executive Summary

ICPerMed (www.icpermed.eu) is a platform of over 30 European and international partners representing ministries, funding agencies, and the European Commission (EC). The central aim of ICPerMed is to align and encourage joint efforts in personalised medicine (PM) research and implementation. This is the report of the Second ICPerMed Workshop, entitled "PERSONALISED MEDICINE FOR ALL CITIZENS AND PATIENTS WITHIN SUSTAINABLE IMPLEMENTATIONS", which took place in Madrid from November 5-6, 2019.

The workshop facilitated the exchange of experiences and ideas between ICPerMed members and international high-level experts in personalised medicine (PM). It was organised around four parallel working groups focusing on four topics:

WG I
Personalised medicine: How do we ensure awareness and empowerment for all citizens?

WG II
What are the ethical, legal, and social implications (ELSI) of personalised medicine research and implementation?

WG III
Transfer of research results into the market: How do we optimise a safe, rapid, and economically viable process to implement personalised medicine approaches?

WG IV
Personalised medicine in the health system: How do we ensure sustainability and effective collaboration between all healthcare players,
as well as with prevention services?

During the workshop, the working groups achieved strategic recommendations that will enable ICPerMed to prioritize the next steps in terms of the implementation of PM, in line with its own objectives. A set of recommendations was developed, with certain conclusions that were common to all panels, indicating the necessity to increase efforts in the following areas:

- Building trust among all sectors: research, the healthcare system, all healthcare players, the patient community, and society.
- Building trust among all stakeholders in PM research based on high quality data, regulatory pathways, training, and data management, etc.
- Building trust within healthcare systems and among health-policy makers for PM approaches.
- Recognising the need for greater patient empowerment in co-authoring their own future.

The outcomes of the Second ICPerMed Workshop are published by ICPerMed and will be integrated into future recommendations, guidelines, and strategic publications.

II- Workshop Introduction

The Second ICPerMed Workshop on PM "PERSONALISED MEDICINE FOR ALL CITIZENS AND PATIENTS WITHIN SUSTAINABLE IMPLEMENTATIONS " was hosted by the National Health Institute Carlos III, Spain, with financial support of the European Commission.

The workshop was structured around plenary sessions and parallel working-group sessions:

- An open plenary session
- Two keynote lectures
- Panels of the four Working Groups

  WG I
  Personalised medicine: How do we ensure awareness and empowerment for all citizens?

  WG II
  What are the ethical, legal, and social implications (ELSI) of personalised medicine research and implementation?

  WG III
  Transfer of research results into the market: How do optimise a safe, rapid, and economically viable process to implement personalised medicine approaches?

  WG IV
  Personalised medicine in the health system: How do we ensure sustainability and an effective collaboration between all healthcare players, as well as with prevention services?

- The ICPerMed 'Best Practice in Personalised Medicine' Recognition 2019 Award ceremony
- Vision Paper 2030
- A final plenary session of closing remarks

III- Plenary Session: Welcome & Introduction

The Chair of ICPerMed, Jan-Ingvar Jönsson, introduced the ICPerMed consortium to the auditorium. The international consortium was launched in 2016, in parallel with the ICPerMed Secretariat, and has now more than 40 European and international partners represented by ministries, funding agencies, and the European Commission (EC), with the aim of coordinating and fostering research to develop and evaluate PM approaches.

ICPerMed members work to make ICPerMed a global leader in the field of PM. One of the keys to success is to support science through a coordinated approach to research. One of the main goals within activities of ICPerMed, and an important task for the workshop, is to reach out to patients, citizens, and the various actors of healthcare systems.

Together with various related initiatives focusing on various areas of PM, ICPerMed is forming an "ICPerMed family", including ERA PerMed as a funding instrument.

ICPerMed works as a consortium and focuses on specific areas of interest. These efforts are guided and coordinated by the **Action Plan (2017)**, which focuses on 30 action items, of which 22 are related to research activities and eight to research-supporting activities.

For ICPerMed, the events organised by the consortium are important for reaching out to the scientific community. In addition, **ICPerMed's chair, Jan-Ingvar Jönsson**, also highlighted the importance of best practice examples on a regional level. Best practice awards in PM are essential to show successful implementation of research evidence into practical healthcare and treatment. In addition, he emphasized the importance of the ICPerMed Action Plan and **Vision Paper 2030**.

The Vision Paper presents the future vision of ICPerMed in PM research and implementation by 2030, based on consultation with European and international experts, covering a range of relevant sectors and professional backgrounds.

The **European Commission representative, Carmen La Plaza Santos**, introduced the Commission's perspective on PM as the core of the research funded by the European Commission over the last decade. She highlighted how PM is already implemented in areas such as oncology and how it is moving forward to replicate this success in other contexts in various regions and member states.

She outlined the efforts and advances made thus far to start regarding PM as a substantial savings to healthcare budgets and therefore making it available to all patients, using pharmacogenomics research as an example of how adverse reactions and ineffective treatments can be reduced.

Keeping in mind the demonstrated effectiveness of other actions that promote healthy lifestyles and vaccination, another important opportunity lies in the area of disease prevention. In this context, personalised profiling is still in its infancy, showing great opportunity but also high budget limitations in current healthcare budgets.

During the Research and Innovations Days, organised in Brazil, the stakeholders identified prevention as a key aspect of PM for the next research programme.

PM holds many promises and there have already been many successes, but there are also many issues that need to be tackled to make PM a reality for all. The main priorities for the European Commission concerning PM are:

- Data management, utilization, analysis, infrastructure, and protection
- Cross border collaboration from a European Union perspective to be able to share lessons learned by others and try to replicate successful practices
- Interdisciplinary collaboration to involve stakeholders, patients, citizens, and healthcare providers
- The necessity of specific training for future healthcare workers

The initiatives of the European Commission related to PM are:

1. Three pilot grants for PM with an estimated budget of 20M€ to demonstrate the piloting of PM in other areas, such as cardiology and diabetes.
2. Continued financing of PM in the next framework programme through a partnership that could start in 2023, in which ICPerMed and ERA PerMed will be important contributors.
3. Expected access to at least 1M genome sequences in the European Union through The One Million Genome initiative by 2022, already signed by 20 member states and Norway.

The next framework program of the EC, Horizon Europe, will ensure an increase in the impact of research and innovation funding, investing more into the impact of Research and Innovation actions. Horizon Europe will thus seek more synergies with other funding programmes to encourage the faster uptake of research results by the clinic at the regional level.

Raquel Yotti Alvarez (General Director, National Institute of Health Carlos III (ISCIII), Spain) welcomed the Workshop participants and presented a description of the ISCIII aims and objectives. She highlighted the position of ISCIII as a promoter of health research. The strategic position of ISCIII ensures a link between research and health, which is essential to promoting the implementation of PM for all citizens. Finally, she thanked the ISCIII staff for preparation of the event, giving thanks to Gonzalo Arévalo Nieto and especially Rafael De Andrés Medina for his long-term efforts concerning ICPerMed and PM in general.

Finally, the Spanish Secretary General for Scientific Policy Coordination, **Rafael Rodrigo,** presented Spain as a strong player in biomedical research. Results achieved thus far demonstrate that Spain is one of the leading countries coordinating grants in which PM is a part. The Spanish Government believes that, under Horizon Europe, Spain can consolidate and improve this position, not only in performing research but also in its programming at the level of the European Union. He underscored the importance of ISCIII as the main public funding agency for biomedical research. ISCIII plays a dual role as one of the main actors for the national research and innovation system as well as its responsibility in better rating biomedical health research. PM has always been represented in the Spanish research agenda and Spain has shown commitment towards PM at a European level by coordinating the ERA PerMed programme.

IV- Plenary Session: Keynote lectures

Liisa-Maria Voipio-Pulkki, Director General and Chief Medical Officer of the Ministry of Social Affairs and Health, Finland, presented the first keynote lecture. She shared a number of the Finnish experiences on the strategic challenges of implementing PM in health systems.

Health is an important issue for the Finnish government. The implementation of PM started as a journey three years ago as a collaboration between ministries and public funders of research and innovation. It started as an initiative to promote academic research but has transformed into a model for the sustainable development of PM and the implementation of personalised healthcare.

The secondary use of primary generated data will not only benefit PM but also society in general by boosting research and medium-sized companies, as well as by being available for the authorities to monitor and follow the impact of policy on health and the social care system using real data.

The Finnish government is systematically investing in the infrastructure for PM in terms of research, innovation, education, and data management centres of excellence. This is exemplified by the Finnish Cancer Centre (started in 2019) as an infrastructure rooted in the healthcare system to safeguard equal access to cancer treatment in the future, with an eye towards PM.

She also described the Genomics Policy Brief and Finland's Genome Strategy to enable the effective use of genomic data in healthcare. She presented the FINDATA registries, in which a substantial amount of data will be combined with personal IDs to enable secondary use of these data, following the General Data Protection Regulation (GDPR) and specific legal regulations. She explained how building a sustainable PM ecosystem is a joint venture of companies, authorities, researchers, and healthcare providers. It is essential to develop legislation and ethical principles, create an open environment and public-private partnerships, and seek professional excellence and a dialogue with the healthcare system and public health experts. Another important element is to maintain the trust of patients and society to achieve sustainable implementation of PM.

One expert from the audience asked whether the Genome Centre was going to collect and register genomic data from patients throughout their lifetime or for just a short period. Liisa Maria described the permanent reference database and introduced a new question about what data should be collected. In addition, due to the expected secondary use of the data, it will be stored in an electronic health record system and will always be available, according to the secondary use legislation.

The second keynote lecturer was Claire Gayrel, Legal Officer of the European Data Protection Supervisor. The European Data Protection Supervisor is responsible for monitoring compliance with data protection laws by EU institutions and for advising their legislators on any new rules and policies that have an impact on data protection and privacy rights.

Personal data is critical to ensuring the quality and reliability of PM. At the same time, genetic, biometric, and health data are considered to be sensitive, of which its use can affect individuals and society.

Scientific research occupies a privileged position in the GDPR. The GDPR encourages innovation and gives knowledge priority. It provides several derogations and exceptions for certain fundamental principles of data protection, for example, the purpose limitation principle. The GDPR provides a lighter scheme for research, which is justified by the importance of science to society. This does not mean that the GDPR allows endless retention and the use of data by anyone for any purpose. She

highlighted that GDPR compliance is essential for implementing PM and the GDPR should be seen as an instrument instead of an obstacle in the field of PM, encouraging scientists in its implementation, since the GDPR allows the standardization of data protection and data privacy.

One expert from the audience expressed concern about the large amount of information contained within genomic data and Claire agreed that new methods of interpretation and discussion are needed to see how far society empowerment should go. Another expert requested her opinion about the conservative interpretation of the GDPR performed by ethics committees and she explained that the divergences in interpretation of the GDPR between ethics committees and data protection authorities should be resolved and that the GDPR is under a two-year review process to improve it. It was also highlighted by members of the audience that several countries have various initiatives to standardize the code of conduct for health research records.

V- Plenary Session: Working Group Panels

Working Group I. Personalised medicine: How do we ensure awareness and empowerment for all citizens?

- Chair: **Dr. Sabrina Montante** (National Institute of Health of Italy/ISS, Italy)
- Vicechair: **Dr. Marta Puyol** (Spanish Association Against Cancer Scientific Foundation, AECC-FC, ES)
- Rapporteur: **Dr. Terje Peetso** (North Estonia Medical Centre/NEMC, Estonia)

The focus of the session was to analyse the factors that could ensure the awareness and empowerment of all citizens in the field of PM, focusing on the role of health literacy in patient empowerment, transformation of the role of the patient towards the disease through data management, and patient and public engagement with their health services.

The major challenges for the transformation of the role of the patient towards the disease that must be addressed are citizen access to health data, the wider use of (standardized) PROMs and PREMs, interoperability of data remotely collected by patients, and the involvement of physicians in improving patient input. Patient engagement was brought into focus by recognising the need for greater patient empowerment in co-authoring their own future.

To this end, mapping the existing tools, experiences, and needs is essential, combined with improvement of the understanding of PM by all healthcare professionals through various channels, study cases, and experiences across regions and countries.

To increase literacy, it will be important to rely on trustworthy sources of information (online courses, specific tools...), involve patient advocacy groups, and modernise patient information leaflets. Access to data and data generation is very important for raising awareness of the importance of the digital determinants of health. Digital programmes must be integrated into national programmes to enable the establishment of PROMs and PREMs in PM and provide information to patients on clinical trial results.

Another challenge is the implementation of the EU recommendations (incl. interoperability) at the national, regional, and municipal levels. Patient and public trust of their health services must be built by social networking, considering patient advocacy groups as peer groups, or using scientific results as examples related to PM.

Working Group II. What are the ethical, legal, and social implications (ELSI) of personalised medicine research and implementation?

- Chair: **Prof. Dr. Anne Cambon-Thomsen** (Inserm & University of Toulouse III, France)
- Vice-chair: **Prof. Dr. Gaetano Guglielmi** (Italian Ministry of Health, Italy)
- Rapporteur: **Prof. Dr. Eva Winkler** (University of Heidelberg, Germany).

The topic to be addressed in WG II was the analysis of all factors that could ensure the awareness and empowerment of all citizens in the field of PM, focusing on the role of health literacy in patient empowerment, transformation of the role of the patient towards the disease through data management, and patient and public engagement with their health services.

Discussions need to be fostered on the ethical and legal aspects concerning the collection, mining, access, and use of data, as well as data security and the involvement of citizens and patients in the decisions pertaining to these issues. Two main perspectives were considered in the discussion: fair access

and technological aspects and identification of the benefits and risks for each type of stakeholder.

Context-specific policies are needed to harmonize and clarify incidental findings and how data is managed. To this end, more research and further collection of experiences into what kind of return policies are meaningful and the long-term effects, experiences, and costs will be helpful.

Patient information, data provision, and the protection of a person's privacy will require that research is sufficiently transparent while still respecting the needs of the participants. Participants should thus be involved in the design of information and consent. At the same time, it is important to start a social debate on the comparison of various consent models and discussion on the processing of large amounts of data and the expectations of PM participants.

In PM, patients are often treated without robust evidence of efficacy. It is thus, important to consider the risk of side effects and the cost. Data collections will thus need to be interoperable across countries and regions and evaluated based on guidelines for quality control and conflict of interest.

Working Group III. Transfer of research results into the market: How do we optimise a safe, rapid, and economically viable process to implement personalised medicine approaches?

- Chair: **Dr. Anna Rita Franco Migliaccio** (University of Bologna, Italy)
- Vice-chair: **Dr. Sebastian Delbrück** (VDI/VDE Innovation + Technik GmbH, Germany)
- Rapporteur: **Prof. Fr. Jacques Demotes** (ECRIN, France)

The discussion of WG III was focused on the transfer of research results into the market in the PM field. They addressed the technological challenges facing PM research and highlighted the importance of data quality and reproducibility, as well as the importance of establishing data collection strategies and methodological standards for PM studies. This methodological standard would make it possible to guarantee that the market authorization process would adopt PM studies and that they would have strict regulations regarding diagnoses and the use of medical devices. Market and regulatory issues must be addressed to facilitate access to PM and its implementation.

The main conclusions of the discussion were grouped around the following questions: what should be considered specific to PM in the development of health products; what is the funding mechanism for PM development programmes; and what is the evidence required for them to be embraced by health technology assessment (HTA) /insurance?

Certain requirements must be met to address these questions, such as multidisciplinary and specialised support in the development plan, training in new skills, and knowledge of the costs of PM for healthcare systems.

The roadmap for the next steps highlighted the importance of building on knowledge through training, support, and expert advice. The second important aspect is that involvement of HTA and health insurance is important for understanding what the economic value of PM solutions will be after additional identification of industry expectations and additional venture capital investment.

Working Group IV. Personalised medicine in the healthcare system: How do we ensure sustainability and an effective collaboration between all healthcare players, as well as with prevention services?

- Chair: **Prof Dr. Avi Israeli** (CSO, Ministry of Health, Israel)
- Vice-chair: **Dr. Ricardo Pereira** (Foundation for Science and Technology, Portugal)
- Rapporteur: **Dr. Toni Andreu** (EATRIS-ERIC, The Netherlands).

The discussions of WG4 were based on sustainability and effective collaboration between healthcare players and prevention services. They analysed factors that could ensure the sustainability of PM in the healthcare system and an effective collaboration between all healthcare players and prevention services. PM represents a translational pipeline in which the individual is at the centre of the entire process.

This process must be efficiently designed to guarantee efficient incorporation into the clinical decision-making setting and the portfolio of services of healthcare systems. Therefore, technological and process-oriented barriers must be identified and specific solutions must be developed and implemented. Various "personal" aspects must be considered to be prepared for a truly personalised approach.

The creation of roadmaps and action plans with clear objectives and a set of criteria to define strategies in the creation of a portfolio of successful cases of PM, together with the creation of policy materials and an integrated pipeline adapted to national/regional societal reality, would be helpful.

Collaboration between all healthcare players could be ensured with cooperation between international organisations, as well as the patient community, for adopting PM interventions. This could be achieved by promoting the creation of a forum of policy makers, developing a framework to assess the efficiency of outcomes of PM interventions, and developing specific training programs and integrating the research community into the healthcare community.

VI- Plenary Session: ICPerMed 'Best Practice in Personalised Medicine' Recognition 2019

Jan-Ingvar Jönsson (ICPerMed Chair) introduced the awards ceremony for ICPerMed "Best Practice in Personalised Medicine" Recognition 2019. This awards ceremony represents the opportunity to honour and promote good examples of PM implementation, making a difference, and encouraging others to bring forward their examples.

The winners of the ICPerMed "Best Practice in Personalised Medicine" Recognition 2019 were:

1. **Patrizio Giacomini (Oncogenomics & Epigenetics, IRCSS National Cancer. Institute Regina Elena, Rome, Italy).**
   A Liquid Biopsy 'hub': integrating nano-technologies to improve cancer diagnosis and therapy.

Patrizio Giacomini is a researcher from the IRCSS National Cancer Institute Regina Elena, Rome, Italy. He presented the results obtained from a clinical trial based on the use of a liquid biopsy "hub" based on nanotechnologies to improve cancer diagnosis and therapy. Initial results show how the use of such technology is able to rapidly reveal clonal section and the evolution of cancer after treatment, with the sensitivity of a digital PCRP.

Two systems were used for nanodrug development and delivery: TOOLBOX and nano-ferritin. Based on their solid and innovative industrial process, they plan to enter into the development phase and clinical trials. The nano-caging system shows a wide drug and tumour target spectrum, favourable pharma-cokinetics, encouraging therapeutic efficacy, and high flexibility,

It is not clear whether this approach will become a true therapy, but Patrizio added that it is important to keep it in mind in terms of future therapies because combination drugging and targeting using liquid biopsy may guide the administration of drugs in future therapies. The prize received by ICPerMed will help finance the Precision Oncology Open Day.

2. **Juergen Busch (Ludwig Boltzmann Gesellschaft, Austria).**
   Best Open Innovation in Science Practice for the Establishment of Interdisciplinary & Inter-Sectoral Collaboration. Platforms for the Implementation of Personalised Medicine. Ludwig Boltzmann Institutes for Digital Health.

Juergen Busch, from the Ludwig Boltzmann Gesellschaft, has established interdisciplinary and intersectoral collaboration platforms for the implementation of PM through open innovation in science. With their new initiative, they proposed the creation of two new public-private institutes related to research in transnational activities in the domains of digital health and PM, with an estimated budget of 10M€ each for a funding period of seven years. To support these institutes, they developed a competitive four-stage open innovation in science (OIS) process for spending and distributing these funds:

I. Five potential strategic topics were identified based on an expert opinion and stakeholder crowd sourcing and an international jury selected two of them.

   a) Topic 1: Specific aspects of increasing the contribution of patients to diagnosis, treatment, and after-care.
   b) Topic 2: Specific aspects of securing and enhancing the quality of healthcare services and patient safety.

II. Partners between hospitals and universities were identified during an informative workshop. They organized a call of interest and established a consortium for each of the retained topics.

III. Development of the research questions that were included in the call for an ideas lab.

IV. Building of research teams.

Once these research teams were selected, they pitched their ideas in front of the international jury on the last day of the ideas lab and had the opportunity to develop a full research plan for seven years. After another external review, both plans were approved and selected.

- Topic 1: The objective is to provide personalised, long-term, sustainable, efficient, and effective support to patients for health-promoting behaviour to reduce the risk and consequences of cardiovascular diseases. (Salzburg)

- Topic 2: The institute will address patient safety and health literacy in a pervasively digitalised environment, addressing questions of the application of data science, data ownership, empowerment, legal frameworks, education, and uncertainty in data in a personalised, patient-centric manner. (Vienna).

3. Sulev Resiberg (University Tartu STACC, Quretec, Estonia).

Translating genotype data into clinical pharmacogenetic recommendations: challenges and solutions.

Suley Reisberg, a researcher from the University of Tartu, Estonia, presented the developmental process of an algorithm that allows them to provide personal pharmacogenetic counselling for gene donors to the Estonian Biobank and a more detailed overview for the doctor, with recommendations based on the obtained drug-related findings.

Genetic tests are available to detect the pharmacogenetic phenotype from a patient sample, but they are quite limited, only targeting single genes and few genetic markers. They want to develop more comprehensive testing, turning the existing knowledge of pharmaco-clinically important genes into a computer algorithm and predicting the pharmacogenetic phenotype of 44.000 participants of the Estonian Biobank. Based on this method, 99.8% of the participants require personalised adjustment for their treatments.

There has already been an impact; Estonia has a national project to build a national IT infrastructure to provide pharmaco-genetic recommendations for doctors that will be built into the national online digital prescription system. At the same time, they are working on improving the algorithm and updating the procedures and documentation to meet the requirements of medical-device regulation and those of in vitro diagnostics.

4. Mark A.Rubin (Department of BioMedical Research (DBMR), University of Bern, Switzerland).

Development and integration of organoid models in personalised medicine platforms.

Mark A. Rubin, from the University of Bern (Switzerland), presented the development and integration of organoid models in PM platforms. They developed a new model and screening method for drug testing based on organoids.

Organoids are cells taken from a patient sample and grown in the laboratory. They lack a complex microenvironment and are less heterogeneous than patient samples but are difficult to maintain in culture. They compared the activities for which these organoids can be useful with the same activities using regular patient-derived xenografts (PDX) as an illustration of their application. The results showed that organoids allow quicker testing and the creation of stable lines over time.

Organoids are useful for drug screening and testing. As proof, they analysed the responses to treatments comparing the data obtained using organoids and that from PDX. The results obtained were similar between the various experiments, allowing them to conclude that organoids can be used as a new model and screening method for patient treatment.

VII- Plenary session: Vision Paper 2030

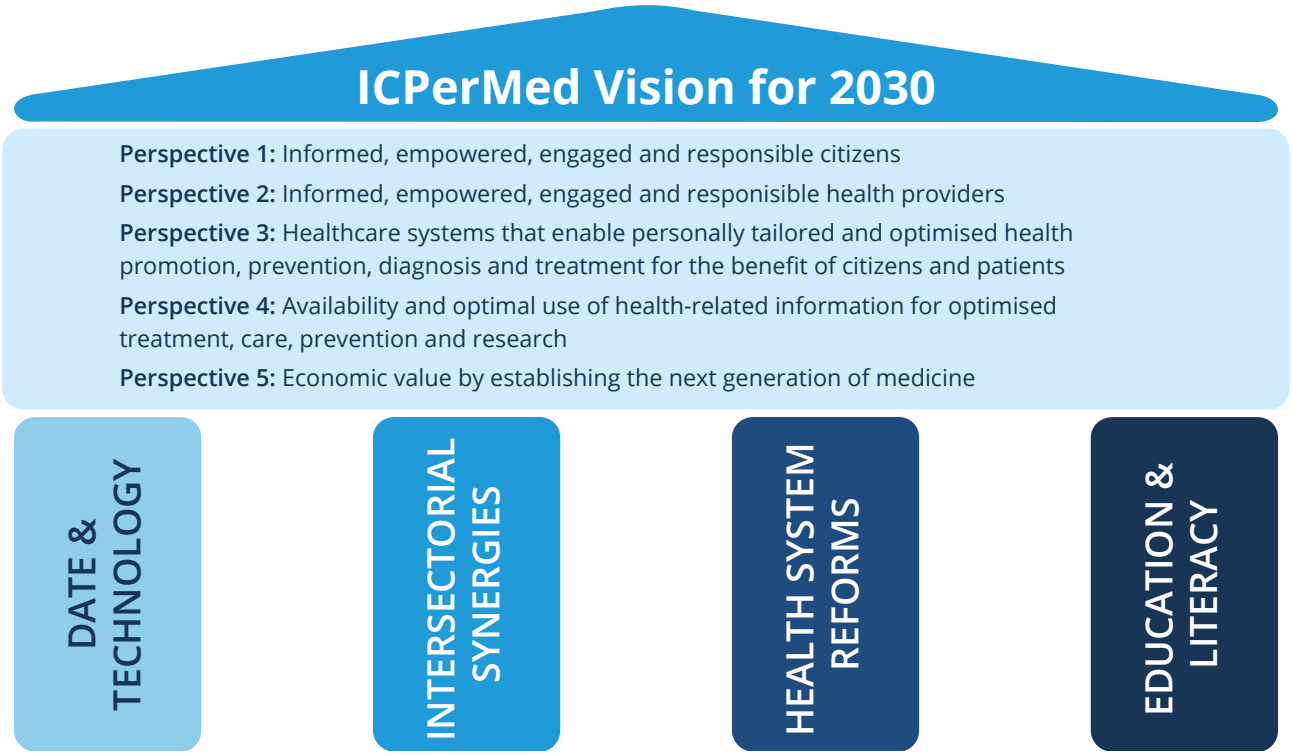
Astrid Vicente (Instituto Nacional de Saúde Doutor Ricardo Jorge, Lisbon, Portugal), as ICPerMed Vice-Chair, presented the ICPerMed **Vision Paper 2030** "How can personalized approaches pave the way to next-generation medicine?" She explained the current context, with the ongoing changes in healthcare in terms of technology, the digital revolution, the focus on patients, the sustainability of the healthcare systems, and an increasingly engaged society with expectations for health and quality of life.

The idea was to assess how PM may look in 10 ten years to set objectives and see how to attain them. ICPerMed has been working on this issue for a long time and has developed an **Action Plan** that includes numerous crucial topics.

The Vision Paper 2030 expresses the aims in PM that should be achieved by 2030 and the path that should be followed to achieve them and includes five perspectives in PM:

- Citizen and patient empowerment
- Health professional education and awareness
- Healthcare system to ensure optimal access to care
- Information infrastructure and management
- Recognition of economic value

Along with these five topics, the ICPerMed Vision Paper establishes four cross-cutting pillars that affect them: data and technology, inter-sectorial synergies, health system reforms, and education and literacy.



VIII- Plenary Session: Wrap Up & Closing Remarks

Ulrike Busshoff, coordinator of the ICPerMed Secretariat, presented a brief summary of the main thoughts extracted from the Working Group discussions and recommendations. The following common denominators were identified within all Working Groups:

One is building trust across sectors by improving the mechanisms that are currently being used (research, healthcare systems, and society). Another key issue is building trust among all stakeholders in PM research by providing high quality data from multiple sources, training scientists in data management and analysis, involving regulatory pathways, and increasing patient involvement.

For healthcare system and health policy decision-makers, the training of healthcare professionals was a big concern, as well as promoting a systemic change by creating an integrated PM pipeline adapted to national and regional realities, providing evidence for the feasibility of PM, the provision of a portfolio of success stories by ICPerMed, and ICPerMed serving as a forum for policy-makers from the healthcare domain.

Indridi Benediktsson, member of the European Commission, expressed the gratitude of the European Commission to the organizers of the event and ICPerMed, as a whole, for all that has been achieved. He addressed the importance of events such as this Workshop due to the multidisciplinary nature of the discussions and their importance when facing new challenges as a consortium. The EC believes that the coming years will be crucial for the future role of PM in national healthcare systems, a role in which PM has an important role to play.

Raquel Yotti Álvarez congratulated the organizers for the success of the event, which she highlighted as being very useful in the implementation of PM. She encouraged everyone to continue the work on the issues identified and discussed in the working groups. She also congratulated the winners of the "Best Practice Recognition" award and pointed to them as examples to develop and illustrate the common agenda.

She highlighted the work that Spain is doing in other initiatives, such as ERA PerMed, EULAC PerMed ,and One Million Genomes. Looking to the future, she highlighted the importance of building new partnerships in Horizon Europe based on what has already been achieved and established.

Pilar Aparicio Azcárraga, Director General of Public Health, quality and innovation, brought the support of the Ministry of Health. She highlighted and explained the development of the Spanish healthcare system as an example of a developmental process with an integrated vision of health that is now evolving into PM. She highlighted the challenge that ISCIII and the Ministry of Health have accepted to advance and make PM effective. She also congratulated all the attendees for the daily work completed and the organisation of the event as a way to obtain new strategies and tools for the future.

Finally, **Jan-Ingvar Jönsson** acknowledged the work of ISCIII and the Ministry of Health in its role as a partner in European and international collaboration for research and implementation in PM. Additionally, he thanked all participants for managing to create an event with a broad perspective, open to different opinions and suggestions.