

# State of the Art Report 2018



# 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 The French National Funding Agency (ANR) (Dr. Monika Frenzel, Dr. Jeanne Guihot and Dr. Michael Joulie), on behalf of the International Consortium for Personalised Medicine, ICPerMed.

## Acknowledgement

This document was developed with the help of the ICPerMed Secretariat and ICPerMed Steering Board with the approval of the ICPerMed Executive Committee.

## Contact

The French National Funding Agency (ANR)  
Dr. Monika Frenzel  
E-mail: [monika.frenzel@agencerecherche.fr](mailto:monika.frenzel@agencerecherche.fr)

ICPerMed Secretariat  
Dr. Ulrike Bußhoff  
E-mail: [ICPerMed@dlr.de](mailto: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

October 2019

## Design and layout

Andrea Nolte | DLR Project Management  
Agency

## Links to external websites

This ICPerMed State of the Art Report 2018 contains links to external third-party websites. These links to third-party sites do not imply approval of their contents. DLR Project Management Agency has no influence on the current or future contents of these sites. We therefore accept no liability for the accessibility or contents of such websites and no liability for damages that may arise as a result of the use of such content.

## Using the content and citation

If you wish to use some of the written content, please make reference to: The ICPerMed - State of the Art Report (2018).

# Contents

|  |    |
|--|----|
| Executive Summary  | 4  |
| State of the Art Report 2018   | 5  |
| 1. Development of ICPeMed and steps taken towards internationalisation | 5  |
| 2. ICPeMed's mapping activities  | 5  |
| 3. ICPeMed Action Item Groups – follow-up on the Action Plan           | 10 |
| 4. Towards the identification of Examples of Best Practices            | 11 |
| 5. Position of ICPeMed in the PM environment                           | 12 |
| 6. ICPeMed events/activities in 2018                                   | 13 |
| Outlook  | 14 |
| Annex  | 15 |

# Executive Summary

With its second State of the Art (StoA) Report, ICPeMed seeks to share information on the consortium's activities and achievements during the November 2017 to October 2018 period. Besides general information about ICPeMed's activities (meetings, consortium composition, reports/statements developed, etc.), the 2018 StoA report concentrates on the mapping database<sup>1</sup> and the analysis of the data collected/presented.

Since its creation in 2016, the ICPeMed consortium has been constantly growing. Two new members joined ICPeMed in 2017, including one partner from Brazil. The ICPeMed consortium thus made an important step toward the inclusion of more international, non-European partners in the coming years.

In April 2018, Astrid Vicente of the National Health Institute Doutor Ricardo Jorge (INSA) in Portugal was elected as ICPeMed's new vice-chair, replacing Ain Aaviksoo. A new ICPeMed chair will be elected in November 2018 and another new vice chair in the spring of 2019. We are grateful for the support of Mairéad O'Driscoll (HRB, Ireland) and Wolfgang Ballensiefen (DLR-PT, Germany), in their roles as current chair and vice-chair, respectively.

Making progress in Personalised Medicine (PM) also means understanding the PM landscape. Therefore, ICPeMed started intensive mapping activities on different levels including the collection of PM initiatives, platforms, infrastructures, programmes, etc. The outcome of the survey on funding activities in PM, launched within the consortium, is presented in the ICPeMed mapping database. The database is a major product of ICPeMed's activities after the publication of the ICPeMed Action Plan in March 2017. The different mapping activities provide constant follow up on the implementation of the Action Plan. ICPeMed created five working groups to facilitate these mapping activities: The five Action Item Groups.

---

<sup>1</sup> <https://www.icpermed.eu/app/login>

# State of the Art Report 2018

## 1. Development of ICPeMed and steps taken towards internationalisation

ICPeMed is an initiative led by EU Member States and supported with a grant for the ICPeMed Secretariat (2016-2020), a coordination and support action (CSA). Most members are therefore currently from Europe, but ICPeMed seeks to include more international partners in the coming years. Needs and progress made in PM differ between countries and their individual health care systems. The internationalisation of ICPeMed enables the consortium to create a platform to exchange on best practices in PM, with view for future implementation.

In October 2018, ICPeMed had 37 full members and 5 observers from 28 different countries and 4 regions, including representatives from most European countries along with several non-European members from Canada and Israel. Recently, two new members joined the ICPeMed consortium: Fondazione Telethon from Italy and the Oswaldo Cruz Foundation (Fundação Oswaldo Cruz) from Brazil. ICPeMed thus took an important step toward a more international composition of the consortium.

Wider internationalisation of ICPeMed will be underpinned by maintaining and expanding exchanges with its stakeholder group, and notably by collaborating with four new CSAs in PM launched in 2018: two CSAs on regional aspects, one CSA seeking to improve exchanges with the Community of Latin American and Caribbean (CELAC) countries, and one CSA concentrating on healthcare and pharma-economic models for PM. More information will be available on the ICPeMed website.<sup>2</sup>

### Stakeholder engagement and exchanges

ICPeMed also has ongoing exchanges with other stakeholders and initiatives. Representatives of ICPeMed have participated in more than 14 conferences, workshops and meetings organised by PM-related initiatives, presenting the consortium, its achievements and its goals.

The following external speakers were invited to the ICPeMed Executive Committee meeting in Vienna in April 2018:

Prof. Dr Julia Stingl from the Federal Institute for Drugs and Medical Devices in Germany (European “HARMONY” project) and Prof Andre Dekker from Maastricht University in the Netherlands (health research infrastructures for PM).

In reaction to the publication of the One Million Genomes Declarations, ICPeMed published a statement available on the ICPeMed website<sup>3</sup>. ICPeMed is following further developments in the “One Million Genome Initiative” with interest.

## 2. ICPeMed’s mapping activities

Numerous activities in PM are already ongoing on the regional and national as well as the European and international levels. These baseline activities and their outcomes should be collected and communicated as the experiences and knowledge obtained could help to develop larger approaches on a European or even international scale.

ICPeMed performs extensive mapping exercises and is collecting information on the different levels of activities in PM, e.g. funding activities, initiatives, platforms, examples of best practices, etc. This inventory on regional, national, European and international activities in the field of PM aims to **increase the knowledge base** for funders and stakeholders, to **avoid the duplication of efforts** and to **use already existing infrastructures or platforms more efficiently**.

The mapping exercise is furthermore used to monitor progress within the ICPeMed member states toward the Action Plan’s objectives and may serve, for example, to identify crucial research funding topics that can be addressed on the national and/or transnational levels.

<sup>2</sup> <https://www.icpermed.eu/en/related-initiatives.php>

<sup>3</sup> <https://www.icpermed.eu/media/content/ICPerMed%20statement%201%20Million%20Genomes%20Declaration.pdf>



Figure 1: Coverage of ICPeMed member/observer countries participating in the mapping database on funding research in PM. Green: member states that have already provided data on PM funding activities. Blue: member states that have not yet registered PM funding activities in the database.

Internal reporting within ICPeMed and external input such as the results of workshops and conferences, not to mention exchanges with different stakeholders, all provide input for mapping. Outcomes of these mapping activities are communicated by various means. PM funding activities on the programme level are presented in the ICPeMed mapping database.

### Mapping database on funding activities in Personalised Medicine

In March 2017, ICPeMed launched its first internal survey to collect information on funding activities in PM, national/regional funding schemes and general funding information from the participating organisations. Assembled information are presented in the **ICPeMed mapping database**<sup>4</sup> that has been online since 19 June 2018. The database is linked to the ICPeMed website and open to the public after simple registration.

Currently, data from 30 different organisations from 22 countries and two regions are presented. The database is updated regularly and full coverage of information provided from all ICPeMed partner countries is expected within the next year.

The major part of the database concerns information on funding programmes. Additionally, general information about the funding organisations involved is available.

In October 2018, 96 programmes had been identified, i.e. 20% more compared to the survey results in the previous year. ICPeMed has already successfully collected data from 77% of its members' countries and plans to complete the mapping by launching the 2019 edition of the survey (Fig. 1).

As ICPeMed members and observers provide data, programmes presented are mainly supported by Ministries and funding agencies (Fig. 2A). The large number of programmes declared shows the active involvement of ICPeMed partners in PM funding programmes. There is frequently a common contribution by a Ministry and its respective National Funding Agency. In two cases, two distinct ministries (Ministry of Health and Ministry of Research) in Austria and Germany are directly involved in the consortium.

### In total, out of the 96 distinct programmes being presented:

Fifty-two ongoing programmes, or 56%, are dedicated to funding research projects in PM (Fig. 2B). Fourteen programmes are international in character, including 3 European Research Networks (ERACoSysMed<sup>5</sup>, E-RARE<sup>6</sup> and ERA PerMed<sup>7</sup>). The "Personalized Health Initiative"<sup>8</sup> of Canada (third-party country in terms of H2020), for example, demonstrates the global importance of personalised health care, as does the presence of Canada and Israel (as associated country) in several funding programmes. Overall, 27% of the programmes dedicated to PM are international. The main core activity of the participating organisations lays on regional and/or national funding instruments.

Forty-one **programmes**, or 44%, are **not specifically dedicated to PM but allow funding of research projects in this field**; this includes 11 international programmes and 7 programmes co-funded by the European Union's Horizon 2020 research and innovation programme (NEURON Cofund<sup>9</sup>, ERA HDHL<sup>10</sup>, JPND<sup>11</sup>, ERA CVD<sup>12</sup>, EuroNanoMed III<sup>13</sup>, EJP Rare Disease European Joint Programme Cofund<sup>14</sup>, HDHL-

<sup>4</sup> <https://www.icpermed.eu/app/login>

<sup>5</sup> <https://www.eracosysmed.eu/>

<sup>6</sup> <http://www.erare.eu/>

<sup>7</sup> <http://www.erapermed.eu/>

<sup>8</sup> <http://www.cihr-irsc.gc.ca/e/50117.html>

INTIMIC<sup>9</sup>). Similarly, among those programmes dedicated to PM, 27% are international.

Finally, four programmes dedicated to funding PM research were under preparation in 2018.

The different programmes presented in the ICPeMed database tend to focus on early stages of the value chain and on funding for basic, translational and applied research (Fig. 2C). Clinical research is already well represented. This observation could be explained by the fact that the main contributions to the database were provided by Ministries and/or Regional/National Funding Agencies that essentially support public research. However, few industrial funding opportunities have been identified in the ICPeMed database. Among the “other” category, Austria and Germany are developing biobanking research infrastructures<sup>16,17</sup>; Germany is setting up a training/qualification programme called “Interdisciplinary Summer Schools in Systems Medicine”<sup>18</sup>, and Austria created a “National Coordination Platform on Personalized Medicine”<sup>19</sup>, to name just few.

Regarding industrial research funding, 5 out of 18 programmes are funded by the Swedish funding agency Vinnova<sup>20</sup>, which also funds research projects in the upper range of the value chain and embraces innovation and entrepreneurship in new innovative approaches. Vinnova has decided to develop new strategies that are more suited to addressing new challenges and opportunities. “Challenge-driven innovation”<sup>21</sup> is one example of their new funding programme that aims to solve societal challenges through innovation and broad

<sup>9</sup> <https://www.neuron-eranet.eu/>

<sup>10</sup> <https://www.healthydietforhealthylife.eu/index.php/era-net/era-hdhl>

<sup>11</sup> <https://www.neurodegenerationresearch.eu/>

<sup>12</sup> <https://www.era-cvd.eu/>

<sup>13</sup> <http://euronanomed.net/>

<sup>14</sup> <http://www.ejprarediseases.org/>

<sup>15</sup> <https://www.healthydietforhealthylife.eu/>

<sup>16</sup> <http://bbmri.at/>

<sup>17</sup> <http://www.bbMRI-eric.eu/national-nodes/germany/>

<sup>18</sup> <http://www.sys-med.de/en/young-investigators/summer-schools/>

<sup>19</sup> <https://www.personalized-medicine.at/>

<sup>20</sup> <https://www.vinnova.se/en/>

<sup>21</sup> <https://www.vinnova.se/en/m/challenge-driven-innovation/>

Figure 2A

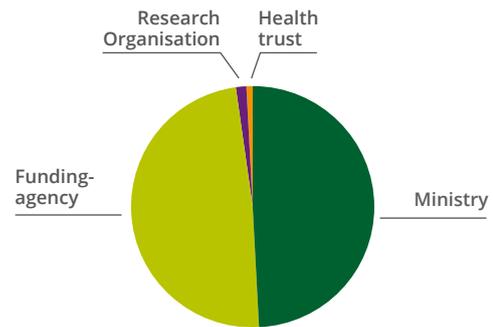


Figure 2B

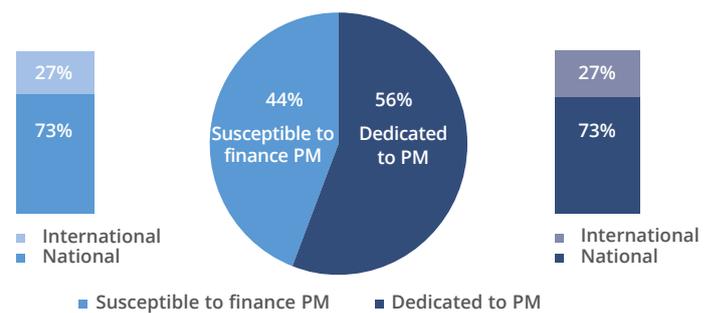


Figure 2C

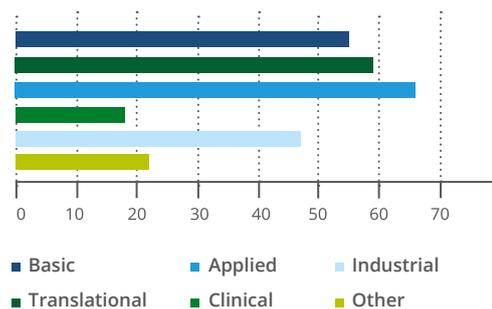


Figure 2:

- Kinds of organisations that registered PM initiatives in the ICPeMed database in 2018.
- Ratio between programmes dedicated to PM (circle diagram, dark blue) and those susceptible to finance PM topics (circle diagram, light blue) with their respective national or international character/nature.
- Types of research being funded in the declared programmes.

collaboration between industry, academic research, public sector activity and civil society. Vinnova has established an innovative, creative, sustainable funding instrument with increasing funding budgets over three stages. In the first stage, the “initiation phase”, collaborations are funded in order to develop new project ideas. In the second stage, a project can apply for further funding aimed at deepening the collaboration between the different actors and to begin developing and testing potential solutions. The third and last step is intended to support the implementation of a business model and to upscale the proposed solutions into the real world. This funding instrument is a good example of how to support projects aiming to implement actions starting from the bench site up to the market.

#### Implementation of the ICPeMed Action Plan:

The main aim of ICPeMed’s mapping activities is to follow-up on the implementation of the ICPeMed Action Plan. For each programme presented, its relation to the 30 actionable Research and Research-Supporting activities is indicated in the database. The Action Items are activities identified by ICPeMed as being essential to achieving full implementation of PM in future. For each subcategory, the number of programmes including at least one Action Item of the respective sections are shown to facilitate data interpretation (Fig. 3A and B). A more detailed analysis for the individual Action Items (AI) is presented in Annex 1. The same programmes may be presented in more than one subcategory.

Figure 3A shows that programmes dedicated to PM (indicated in dark blue) tend to focus more on “cross-cutting” actions and actions around “data” than programmes that are only susceptible to fund PM (indicated in light blue). This highlights the importance of these topics for PM development and implementation.

Overall, all programmes essentially focus their actions on data issues and new technologies, methods and/or processes in PM. Specifically, funding was used to increase the quality, completeness, validity and analysis of datasets and the harmonisation of data (AIs A1, 2, 3, 4, 12; Annex 1). The optimisation of data security, privacy and ownership in PM receives less emphasis, however, despite being crucial to

enabling citizens to become actively involved in their health-care course. Additionally, there is a need to develop common principles and legal frameworks enabling patient-level data to be shared for research.

Moreover, the programmes’ scopes mainly concern the implementation of actions supporting the translation of basic research into clinical research (AIs A9, 10, 13). Actions aimed at funding clinical trials (AI A14), where implementation can be

Figure 3A: Research Activities

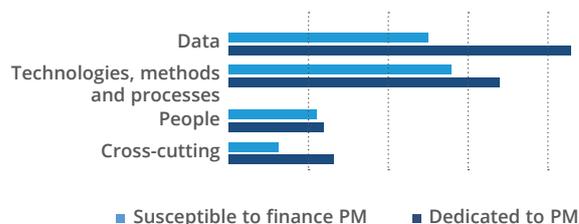


Figure 3B: Research-supporting Activities

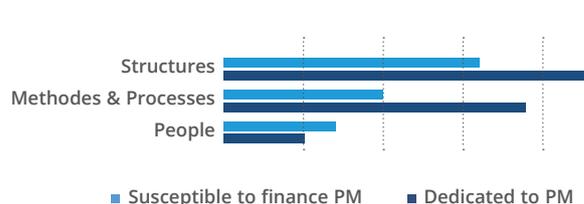


Figure 3: Implementation of the Action Plan. For the analysis, the 30 Action Items are divided into Research and Research-Supporting Actions with their individual subcategories. The same programme may appear in several subcategories if it involves at least one Action Item of the respective category. Indications for the individual Action Items are available in detail in Annex 1.

A. Inclusion of actionable Research Activities in funding programmes presented in the database: The number of programmes dedicated to PM (dark blue) and those susceptible to finance PM (light blue) are compared.

B. Distribution of Research-Supporting Activities for programmes dedicated to PM (dark blue) and those being susceptible to finance PM (light blue).

expected only in the longer-term and not without incremental progress on the ICPeMed Action Plan, are less addressed.

Among all the objectives defined by the Action Plan, funding programmes supporting research in post-marketing surveillance methodologies, aiming at assessing patient outcomes (AI A17), are the least represented, followed globally by programmes promoting PM approaches in a healthy, economically sustainable way (AI A11, 16, 18).

It is encouraging that programmes dedicated to PM are better placed to respond to ICPeMed's objectives than programmes susceptible to finance PM (data not shown), as this suggests that ICPeMed has developed a well-defined set of goals aimed at specifically supporting the implementation of PM approaches by identifying the relevant needs in this area.

For the Research-Supporting activities, figure 3B shows that programmes presented in the database are having overall increased funding activities in promoting the development of new structures, resources and frameworks for implementing PM, such as the development and maintenance of biobanks and population/disease cohorts. Programmes dedicated to PM are notably focused on promoting the development of high-quality sustainable databases for PM-relevant data. Similarly, the following activities are recurrent in programmes dedicated to PM:

- Establish a new collaborative funding organisation model with healthcare providers to develop common strategies in research to support comparative and effective research, and sustainable technology transfer capacities (AI B3);
- Support research to analyse, compare and optimise national and regional health systems in the light of PM implementation (AI B6).

Patient-centred activities are less represented, however, meaning that an effort is needed to develop long-term strategic approaches on how to meet the challenges associated with access to PM from a public health perspective. Nevertheless, compared to all other actions, these objectives are more covered on the regional/national level than on the

international level (Annex 1), probably due to the fact that every country (region) has different healthcare systems and thus, this is an intrinsically regional/national issue.

In summary, the high number of programmes dedicated to PM and those that are non-dedicated but include topics from the Action Plan demonstrates the importance of PM in our societies and the challenges of putting PM in place to the benefit of patients and citizens. The first steps have already been taken, but many challenges still lie ahead as PM is in its early stages, essentially with a need to develop basic knowledge before it can be applied. Efforts are needed in support of research further up the value chain, including strategies on efficient and active citizen and patient involvement/empowerment.

There are many PM approaches on the regional/national level despite the international nature of the topic. Indeed, PM implies a more accurate stratification of patients, and will therefore require larger sample sizes, which can be solved by pooling and sharing knowledge and data across borders. More international initiatives bringing together all the different actors, public and private, are therefore desirable.

The mapping database so far only contains information on funding opportunities mainly supported by ICPeMed members and observers. Although different organisations provided input for some countries, the information collected does not reflect the complete picture of funding opportunities in the field of PM. ICPeMed will continue to collect data on funding programmes and will integrate as well those maintained by organisations and countries that do not belong to ICPeMed.

### 3. ICPeMed Action Item Groups – follow-up on the Action Plan

At the Executive Committee meeting in October 2017 (Lisbon), the five ICPeMed Action Item Groups (AIG) were formed. These active working groups composed of ICPeMed representatives and external experts, aim to follow up on and to work toward the implementation of the ICPeMed Action Plan.

The 30 actionable Research and Research-supporting activities are allocated to the five AIGs with different thematic focuses (concerned Action Items are indicated):

- AIG1: Data and ICT – Enabling Technology (A1, A2, A4, A6, B1)<sup>22</sup>
- AIG2: Data and ICT – Improving Health Care (A3, A5, A7, A8, A12, B7)<sup>23</sup>
- AIG3: Translational Research (A9, A10, A13, A14, A15, B2, B3, B4)<sup>24</sup>
- AIG4: Health Economics, Regulation, Market Access (A11, A16, A17, A18, B5, B6)<sup>25</sup>
- AIG5: People and Society (A19, A20, A21, A22, B8)<sup>26</sup>

The AIGs report biannually on their activities. In the spring of 2018, all five groups concentrated their work on the analysis of funding programmes/activities presented in the ICPeMed mapping database. Furthermore, the AIGs started extensive mapping activities assembling information on PM-related initiatives, platforms, infrastructures, coordination activities, examples of best practices, policy papers/support, etc. So far, over 70 different initiatives have been identified, including CSAs and infrastructures/biobanks, as well as activities on policymaking and dissemination/empowerment, running on regional, national and European levels.

A more detailed analysis of the 70 different initiatives will be performed within the next year. In this State of the Art Report, we would like to mention just three of them:

**The Mayo Clinic's initiative** promoting shared decision-making through the development, implementation and assessment of patient decision aids and shared decision-making techniques through their *"Shared Decision-Making National Resource Center"*. The goal of this programme, in alignment with the ICPeMed's objective to empower citizens, is to identify and evaluate ways to help patients to make well-informed decisions with their clinician via a decision-aid tools by reflecting and respecting the patient's values and goals. A key partner for this activity is the Patient Advisory Group, a group of volunteer patients who meet with researchers to review and discuss research activities since 2004, learning about research, sharing their questions and priorities, and providing feedback on research projects.

The Italian **INNOLABS** initiative accompanying SMEs and start-ups to the market. The initiative notably targets innovative technologies regarding mHealth, with medical device development for self-diagnosis such as wearables.

Several initiatives have been identified for one of the main challenge facing PM implementation: data management. Indeed, data integration and interpretation requires harmonisation to be embedded in healthcare and research systems. Several initiatives have been launched to solve these issues. Among them, **EHR4CR**, now closed, aimed to provide adaptable, reusable and scalable solutions (tools and services) for reusing data from Electronic Health Record systems for Clinical Research. The EHR4CR platform was an open platform that unlocked the information stored in Electronic Health Records for improving clinical research

<sup>22</sup> [https://www.icpermed.eu/media/content/ICPermed\\_Action\\_Item\\_Group\\_1.pdf](https://www.icpermed.eu/media/content/ICPermed_Action_Item_Group_1.pdf)

<sup>23</sup> [https://www.icpermed.eu/media/content/ICPermed\\_Action\\_Item\\_Group\\_2.pdf](https://www.icpermed.eu/media/content/ICPermed_Action_Item_Group_2.pdf)

<sup>24</sup> [https://www.icpermed.eu/media/content/ICPermed\\_Action\\_Item\\_Group\\_3.pdf](https://www.icpermed.eu/media/content/ICPermed_Action_Item_Group_3.pdf)

<sup>25</sup> [https://www.icpermed.eu/media/content/ICPermed\\_Action\\_Item\\_Group\\_4.pdf](https://www.icpermed.eu/media/content/ICPermed_Action_Item_Group_4.pdf)

<sup>26</sup> [https://www.icpermed.eu/media/content/ICPermed\\_Action\\_Item\\_Group\\_5.pdf](https://www.icpermed.eu/media/content/ICPermed_Action_Item_Group_5.pdf)

while fully respecting patient privacy and ensuring a high level of security. The project is now continuing within the environment of the “European Institute for Innovation through Health Data” (i-HD)<sup>27</sup>. The i-HD was formed as one of the sustainable entities emanating from the EHR4CR project. Other ongoing initiatives were also born of this project, notably an early adopter Champion Programme launched as the first step in building a pan-European network of hospital sites connected to EHR4CR implementation: the “InSite” platform<sup>28</sup>. The Champion Programme serves to prove the value of Real World Data for clinical research and EHR4CR/InSite technology on a wide scale.

Finally, the European Commission has launched the **European Open Science Cloud (EOSC)** aimed at providing free, open services for data storage, management, analysis and re-use across disciplines.

## 4. Towards the identification of Examples of Best Practices

The first step towards the implementation of PM lies in exchanging experiences to share knowledge of successful and/or ongoing activities. ICPeMed is fostering these exchanges through different means:

Annual conferences and workshops<sup>29</sup>,

1. The ICPeMed Academy<sup>30</sup>,
2. Collecting examples of Best Practices (BP) and their presentation on the ICPeMed website (in preparation).

The **ICPeMed conference** “Personalised Medicine in Action”, held in November 2018 in Berlin, Germany, will focus on examples of BPs in PM in “research and implementation” as well as “policy”. The presentations in “research and implementation” will consider all the different perspectives of patients, research, clinics, industry and health care professionals.

The **ICPeMed Academy 2018** focuses on the implementation of and training in PM and aims to recognise, encourage, promote and disseminate outstanding examples of BPs in PM. The winners for 2018 will present their work at the ICPeMed conference and will receive support for the dissemination of the examples of BPs by the ICPeMed Secretariat.

Furthermore, **examples of BPs will be presented on the ICPeMed website**. The “story telling” of good practice will be organised by the AIGs as an outcome of the mapping activities.

All these different approaches to presenting examples of BPs seek to demonstrate the shift in PM from theory to practice. The collection of diverse PM approaches and the sharing of experiences are crucial, especially taking into account the diversity of health care systems and the enormous variations between different countries regarding the understanding of PM and the steps to be taken toward its implementation.

---

<sup>27</sup> <https://www.i-hd.eu/>

<sup>28</sup> <https://www.insiteplatform.com/>

<sup>29</sup> <https://www.icpermed.eu/en/activities-events.php>

<sup>30</sup> <https://www.icpermed.eu/en/icpermed-academy.php>

## 5. Position of ICPeMed in the PM environment

As ICPeMed's mapping exercise demonstrates, many activities in the field of PM are already ongoing. Some of them are specifically dedicated to PM; others are more general in character, including some aspects related to PM. There are structural initiatives for creating platforms and/or infrastructures, for example data collection and sharing, biobanking, etc. Others mainly focus on individual aspects such as regulatory, economic and social questions.

Compared to other initiatives, ICPeMed has multifaceted capacities:

- The composition of ICPeMed partners allows exchanges on PM questions on a high regulatory level, since the consortium includes public and private "not-for-profit" health research funding and policy organisations, and thus mainly funding organisations, and notably different types of Ministries.
- High-level participation within ICPeMed enables the consortium to gather information on PM and the political landscape on the regional and national levels, as well as to transmit recommendations to the authorities in the respective countries, such as actions to be taken for the implementation of PM described in the ICPeMed Action Plan.
- Even if funding for the consortium is provided by the European Commission via the ICPeMed Secretariat, ICPeMed has become an international initiative. The global character of ICPeMed enables the consortium to share experiences and knowledge not only across borders within Europe but also to foster exchanges on the international level. Each country contributes to the reflections on PM with its specific experiences and individual health care system.
- ICPeMed's close connection to PM experts enables the consortium to develop strategic documents such as the ICPeMed Action Plan, including the different perspectives of the various key players involved in PM (citizens and patients, researchers, health care providers and professionals, industry, funding organisations and the various regulatory authorities).

- With its annual events (two workshops and two conferences in all), ICPeMed creates synergies and brings together the various actors of the entire value chain (see previous bullet point) to foster exchanges on PM and, most importantly, to demonstrate the shift from simple theory to practice. Outcomes of these events are summarised and published in collaboration with PM experts and shared with the community.
- ICPeMed promotes a common understanding of Personalised Medicine to concentrate and focus all efforts in the same direction. This represents a challenge, taking into account the different type of actors involved in PM (e.g. the general public, professionals, but also regulatory authorities) as well as the different needs, structures and advances of the healthcare systems in the various countries.
- ICPeMed is a platform where research-supporting organisations such as funding agencies and ministries can meet to develop new funding strategies and programmes to foster research in PM. For ICPeMed, support for research is the first step toward the future implementation of PM. For example, the ERA-Net ERA PerMed, closely connected to ICPeMed, is launching annual calls. The different actions in the ICPeMed Action Plan are considered within the scope of calls for proposals. Thus, ERA PerMed is aligning research and funding activities not only on the European level but also internationally.

ICPeMed has successfully managed to provide a flexible framework for cooperation between its member organisations, and is a platform for initiating and supporting communication and exchanges on PM research, funding and implementation. ICPeMed's extensive mapping activities enable the consortium to identify the requirements for a suitable framework in terms of infrastructures, resources and regulatory procedures to foster the development and implementation of PM.

## 6. ICPeMed events/activities in 2018

Between November 2017 and October 2018, the ICPeMed Executive Committee met once in Vienna on 19–20 April, 2018. The second Executive Committee Meeting for 2018 will take place in satellite to the ICPeMed conference in Berlin on 20–21 November in Berlin, Germany.

The first ICPeMed Academy was launched on 19 January 2018, and focused on the following areas:

1. Scientific papers focused on novel approaches for the implementation of PM;
2. Training programmes for health personnel, increasing the level of awareness on the potential of PM;
3. Examples for interdisciplinary or intersectoral groups of collaboration (governmental and non-governmental organizations, academic management, medical research and health care), for the implementation of PM, including Ethical, Legal and Social Issues (ELSI) activities.

In total, 18 proposals were submitted and evaluated by a group of scientific experts in the field. The three top-ranked proposals have been invited to the ICPeMed conference in Berlin and will have the opportunity to present their work during a plenary session. In addition, the successful candidates will receive a non-cash award of €500 to support the dissemination of their examples of BPs.

The following proposals were selected:

- *NAGEN 1000: An example of a Project for Regional Implementation of Personalised Genomic Medicine in Healthcare*; Angel Alonso, Navarrabiomed, Spain.
- *Proposal of Recommendations for a National Strategy on Personalized Medicine Report*; Consuelo Martin de Dios, Fundación Instituto Roche, Spain.
- *In vivo evidence for ribavirin-induced mutagenesis of the hepatitis E virus genome*; Daniel Todt, Twincore, Germany.

Furthermore, ICPeMed has invited four proposals in fourth position to present a poster of their work during the 2018 ICPeMed Conference. These are:

- *Reducing the risk of catheter-associated urinary tract infections via a smartphone application for patients*; Prof Robbert G. Bentvelsen, Leiden University Medical Center, The Netherlands.
- *A Harmonization Study for the Use of 22C3 PD-L1 Immunohistochemical Staining on Ventana's Platform*; Dr Tzahi Neuman, Hebrew University Hadassah Medical Center, Jerusalem, Israel.
- *Nasal chondrocyte-based engineered autologous cartilage tissue for repair of articular cartilage defects*; Prof Andrea Barbero, Universitätsspital Basel, Switzerland.
- *Value of Information Analysis in Personalised Medicine*; Prof Enrico Capobianco, CNR (ISOF) Bologna, Italy and University of Miami, USA.

# Outlook

The ICPeMed consortium, supported by the ICPeMed Secretariat, is successfully entering into its third year after its creation in 2016.

In 2019, the ICPeMed Action Groups will concentrate on the further collection of examples of Best Practices and their presentation on the ICPeMed website as "Story Telling". Please feel free to contact the individual group leaders if you are interested in that working group's topic.

We are looking forward to the first ICPeMed conference on „Personalised Medicine in Action“ on 20-21 November, 2018, in Berlin, Germany, to learn more about the different approaches to the implementation of PM to be presented.

Furthermore, in November 2019, ICPeMed will organise a workshop in Madrid and a second international conference beginning of October 2020 in Paris. We hope to welcome you at one of our ICPeMed events.

# Annex

Annex 1A: Research Activities

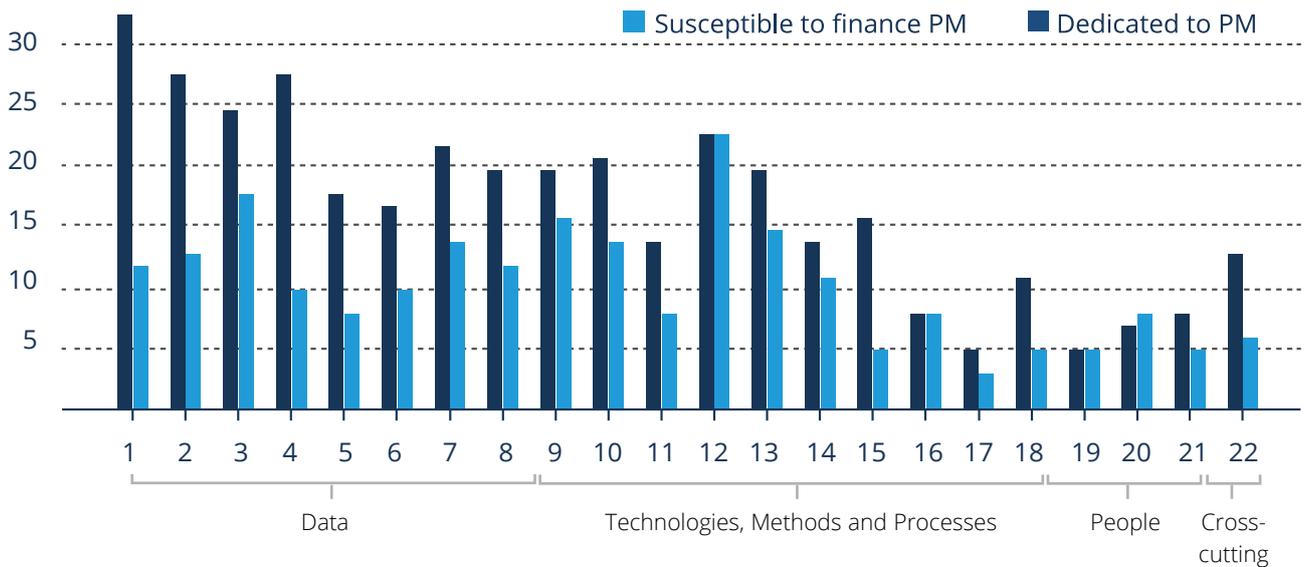


Figure A: Inclusion of the individual Action Items of Research Activities in funding programmes dedicated to PM (dark blue) and those susceptible to finance PM (light blue).

Annex 1B: Research-supporting Activities

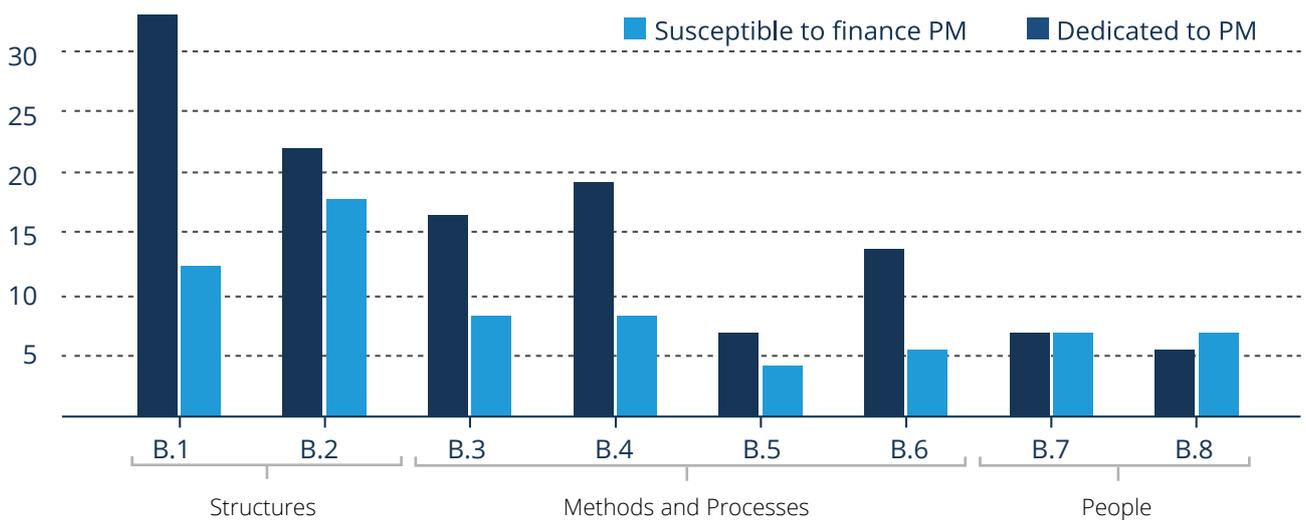


Figure B: Inclusion of the individual Action Items of Research-Supporting Activities in funding programmes dedicated to PM (dark blue) and those susceptible to finance PM (light blue).

