

International consortium for personalized medicine: an international survey about the future of personalized medicine

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Aim: The ICPeMed, international initiative promoting personalized medicine, has realized a survey among a group of experts, to define a common vision for the deployment of personalized medicine across health-care systems until 2030. **Materials & methods:** ICPeMed defined five perspectives (p.4) and addressed an online questionnaire to 97 international experts to collect their views. **Results:** Seventy (72%) of the 97 experts effectively answered the survey from which 69 answers were exploitable. Respondents from a variety of international profiles approved the five proposed perspectives and reported required actions and best practices. **Conclusion:** There is a large consensus among experts directly involved in shaping international strategies and policies, calling for voluntarist public policies, new IT platforms enabling data-driven approaches, large-scale educational programs and new financing models.

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The ICPeMed initiative in Europe & beyond

ICPeMed [1] provides a scientific and political platform for personalized medicine (PM) with the objective to support communication and alignment on research, funding and implementation at an international level. It was launched in 2016 on the basis of the PerMed project that was funded by the European Union's 7th Framework Programme. Aspects of basic research, clinical implementation, citizen empowerment, market access and healthcare systems are addressed within the ICPeMed structure.

Even if there does not exist any commonly agreed definition, ICPeMed's actions are targeting all activities related to the description of PM formulated by the European Council: "[...] personalized medicine refers to a medical model using characterization of individuals' phenotypes and genotypes (e.g., molecular profiling, medical imaging, lifestyle data) for tailoring the right therapeutic strategy for the right person at the right time, and/or to determine the predisposition to disease and/or to deliver timely and targeted prevention" [2].

Members of ICPeMed [3] include more than 40 public and private 'not-for-profit' health research funding and policy organizations primarily from Europe and continuously adding international players. ICPeMed has also built a wide community involving a large range of stakeholders acting at several levels, from basic research to

innovation and implementation, including activities about patient empowerment, market access and healthcare systems transformation. The purpose of this community is to define the future research actions but also the conditions for a suitable framework in terms of infrastructures, resources, public policies and regulatory procedures to foster the development and implementation of PM. ICPerMed initiative aims to bring experts' views and to contribute to the EU collective work for the deployment of PM. ICPerMed activities are aligned with the European Commission's publications and statements about PM [4–7], the EU funding programs [8] and the work of the EU Parliament [9], of the Member states [10] and the main pan-European organizations [11,12].

Based on most advanced scientific work [13–18], PerMed, the project previously developed to ICPerMed, published in 2015 a “Strategic Research and Innovation Agenda” [19] defining five main challenges and the way forward for the PM field and identifying that progresses in PM would require research and implementation efforts along the entire value chain, with the necessity of support through funding programs at national, European and international levels. This publication has been followed in March 2017, by the definition of the ICPerMed ‘Action Plan’ [20]. In order to facilitate consensus building and decision-making processes in a concerted manner across member organizations, ICPerMed has set up five Action Item Groups (Data and ICT – Enabling Technology; Data and ICT – Improving HealthCare; Translational Research; Health Economics, Regulation, Market Access; People and Society) along with five Challenge Groups (Data & ICT; Research Efforts; Market Access; Health Systems; Citizens & Patients) [21]. These groups are in charge of defining the state of the art of on-going initiatives in Europe but also potential roadmaps on specific topics related to PM's challenges.

The ICPerMed Secretariat is ensured by a consortium of several partners (ANR in France, ISCIII in Spain, Ministry of Health in Italy), coordinated by the DLR Project Management Agency, an organization providing services for funding in the areas of research, innovation and education and operating on behalf of German federal ministries, the European Commission, German federal states as well as scientific organizations, foundations and associations.

In November 2018, the ICPerMed organized its first conference titled ‘Personalised Medicine in Action’ in Berlin. Prior to this major event, the ICPerMed Secretariat conducted a web-based survey with experts on PM from all over Europe and beyond with the objective to feed into the discussion around the ICPerMed Vision Paper 2030 [22]. This article presents the methodology behind and the results and conclusions of this survey.

ICPerMed's perspectives on challenges faced by PM: a survey

Methods

Perspectives

ICPerMed's central governance and main decision-making body is the Executive Committee, which includes representatives nominated by the member organizations. Through an iterative process among its members, the Executive Committee shaped five ‘core perspectives’ in order to establish a framework for the survey. These five core perspectives were:

- Perspective 1: Informed, empowered and responsible citizen, including:
 - All health-related data are owned by citizen
 - Data input and access is controlled, supported and monitored by the citizen
 - Easily accessible, reliable and understandable sources of medical information are available, for example, tested and approved apps or internet tools
- Perspective 2: Informed, empowered and responsible health providers, including:
 - Safe and responsible use of health-related information/research results to identify the best prevention, diagnosis and treatment options for each patient, supported by suitable ICT solutions, has become clinical routine
 - Suitable treatment of multimorbid patients, nonresponders and elderly with a minimization of adverse effects is routine
 - The education of healthcare professionals has taken up interdisciplinary PM aspects such as use of ICT in order to access and utilize all available information

- Perspective 3: Health systems enabling personally tailored and valuable treatment and prevention, including:
 - Fair access to healthcare for all citizens independent of socioeconomic status, insurance and residence
 - Optimization of all healthcare services in terms of efficiency, costs and fairness
 - Fair and reasonable allocation of resources within the health systems with consent from society as a whole
 - Appropriate and safe ways have been established for information exchange from citizens to, for example, regulatory authorities or researchers
- Perspective 4: Health-related information/data are available for valuable treatment, care, prevention and research, including:
 - Genome sequencing information, imaging and other diagnostic data/information on a personal basis can be provided by citizens voluntarily to support the health system, for example, via Electronic Health Records (EHR)
 - Solutions for ensuring data privacy, safety and security exist and are harmonized
 - Optimized treatment and prevention impact, while minimizing costs and risks
- Perspective 5: Economic value by establishing the next generation of medicine, including:
 - A reasonable balance of investment and profit is a reality for PM
 - Innovative and appropriate business concepts and models exist
 - Telemedicine solutions and mobile apps promote PM and are of economic value
 - New jobs in the health systems are created, incl. not yet established such as ‘Information/Data Technicians’.

Questionnaire

The survey has been conducted using a questionnaire. The questionnaire was designed with the application PT survey. Programming started in March and ended in May 2018. Within this time period, the survey was pretested by selected experts and adjusted afterward. Because of the different time schedules of the invited experts, the survey was divided into three runs between June and September 2018.

After introducing the purpose and main objectives of the survey and requesting the personal information of the respondent, the questionnaire was describing in its first part the perspectives predefined and proposed by ICPerMed’s Executive Committee.

The second part of the questionnaire was dedicated to collect opinions and information from the respondents about each of the five proposed perspectives. The following series of questions has been used for each perspective. First, a five points Likert-like scale about the agreement or disagreement of the respondent to the perspective (range of answers from ‘strongly agree’ to ‘strongly disagree’). Then, a free text box (limited to 200 characters) allowed the participant to give personal comments and remarks on the perspective. Next item was asking to what extent the perspective was already realized in the respondent’s country and a range from 10 to 100% was proposed to evaluate this progress. Then, the respondent was asked to estimate the horizon when the considered perspective would be achieved in her/his country. The possible answers were: ‘2020’, ‘2025’, ‘2030’, ‘2035’, ‘2040’, ‘late’ and ‘never’. Then, the participant was invited through full text boxes (limited to 100 characters each) to indicate up to three requested steps to reach the full deployment of the perspective. And finally, two optional questions were proposed on potential best practices that the respondent could mention about this perspective and associated references. At the very end of the questionnaire, the respondent was asked from an European point of view, to indicate up to three steps to realize the five missions for the development of PM (through free text boxes limited to 100 characters each). The last item gave the opportunity to the respondent to add general comments and additional remarks on her/his vision for the future of PM (free text box limited to 500 characters). Each item in this questionnaire gave the opportunity to the respondent to select a ‘no answer’ option.

Experts

In total, 97 experts for PM from various countries were invited to participate in the survey. This list, matching with the invitation sent for the ICPerMed conference, has been established by the Secretariat and the Executive Committee among the member organizations of the ICPerMed initiative (national and regional ministries, public and private ‘not-for-profit’ health research funding and policy organizations). Each ICPerMed member has been

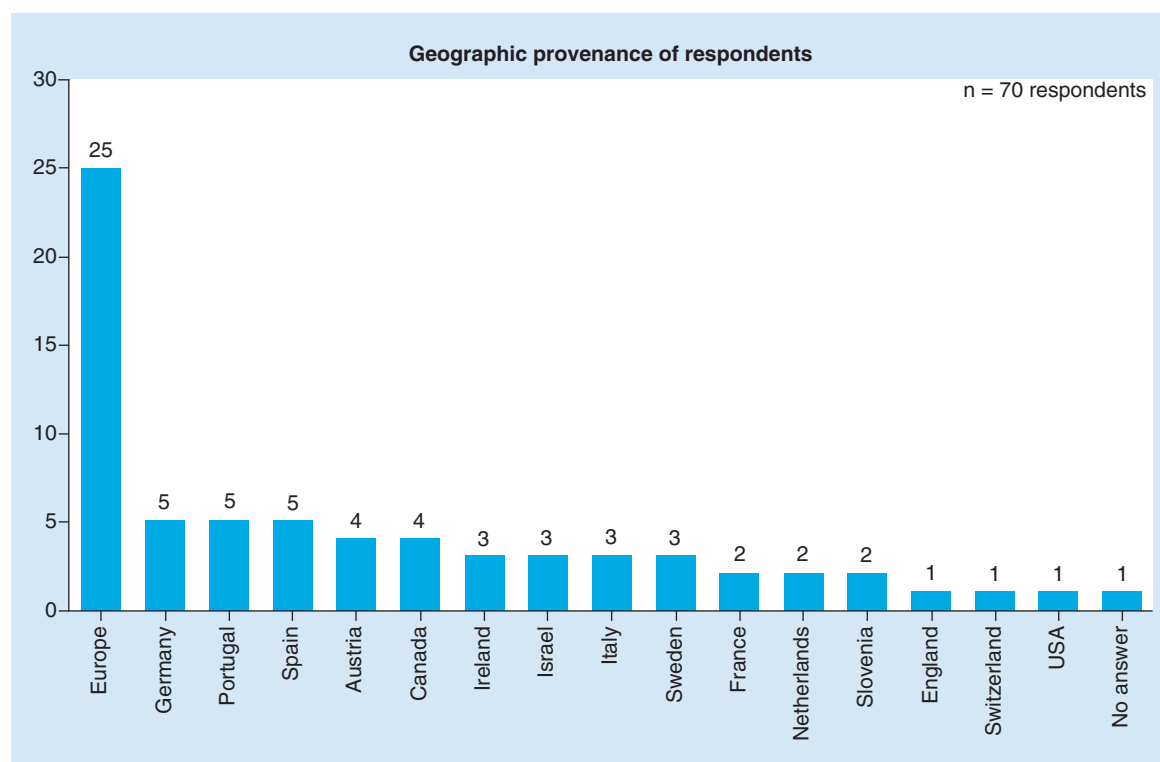


Figure 1. Geographic provenance of respondents.

invited by the ICPeMed Secretariat to suggest a list of experts who they wished to invite to the annual conference and also invited to participate to this survey. Once each member have submitted their list to the Secretariat, they collectively decided the final list of invited experts, paying attention to their representativeness in terms of geography/provenance but also a certain balance in terms of expertise and sectors (e.g., policy-makers, industry, academics, healthcare professionals).

Results

From the 97 invited experts, 70 (72%) completed the survey. The remaining 27 experts (28%) did not answer or open the survey or, as in one case, signed themselves off via 'Opt-out.' From the 70 analyzable answers, 69 were fully completed and one partially.

Participants had the opportunity to answer the questionnaire from a national point of view or from a European perspective. [Figure 1](#) (geographic provenance of respondents) shows the results.

The professional background of the respondents ([Figure 2](#), professional background) reflects the variety of profiles of the nominated experts by ICPeMed, and a majority of respondents are working within research institutions (53%). Healthcare professionals and healthcare providers represent 13 and 4% of respondents, respectively.

The 'Other' (18%) category gathers various profiles such as representatives of policy-makers, patient organizations, payers, IT organizations/companies or further associations or nonprofit organizations. Globally, 11% of the respondents work for an organization from the private sector, 85% within the public sector (and 4% did not answer).

Perspective 1: 'Informed, empowered & responsible citizen'

Perspective 1 'Informed, empowered and responsible citizen' is massively supported by the respondents with 80% of them strongly agreeing or agreeing and 8% disagreeing or strongly disagreeing ([Figure 3](#)).

Forty-eight percent decided to comment on this perspective through the proposed free text box. Most of the comments targeted the point *b* of this perspective 'Data input and access is controlled, supported and monitored by the citizen under EC regulations'. This idea has been challenged especially around the question of the ability of the citizens to effectively control the data access but also their literacy and knowledge, both to make use of the

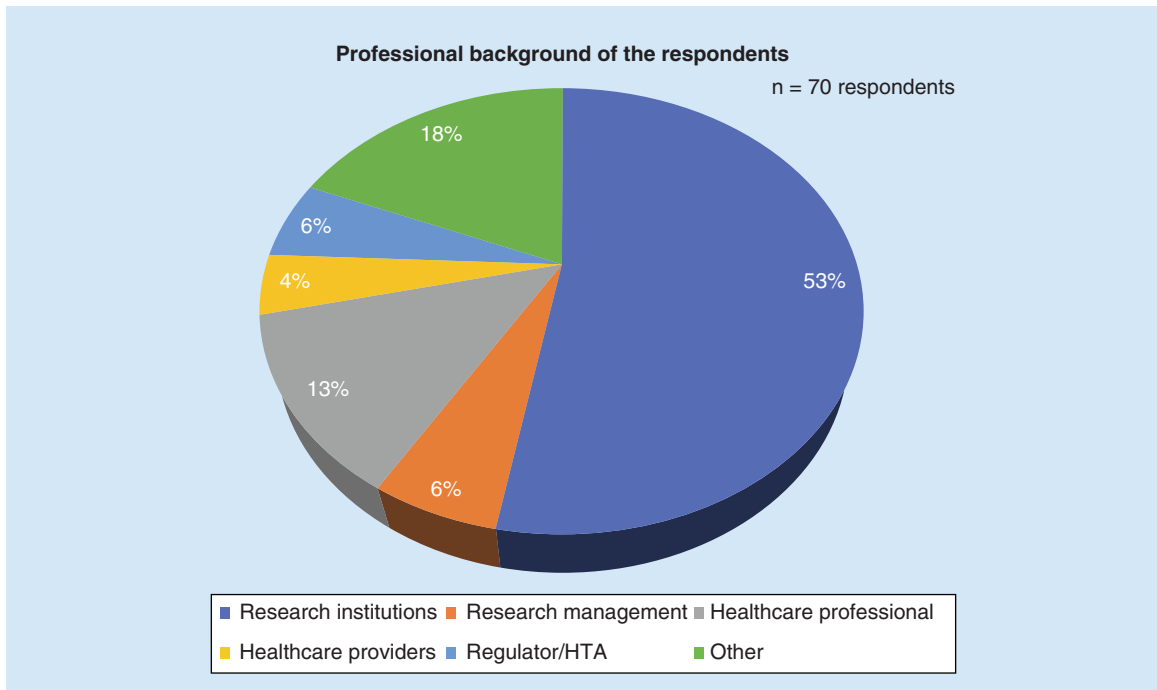


Figure 2. Professional background of respondents.

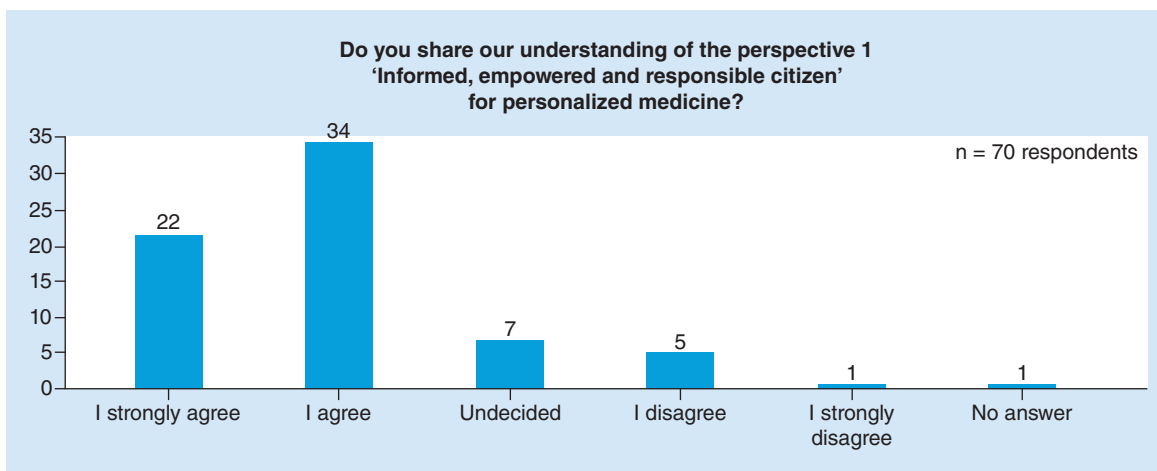


Figure 3. Levels of experts' agreement with Perspective 1.

data and to perceive the strategic need of these data for the healthcare systems. In doing so, the respondents were underlining the equilibrium to keep here, between the rights of citizens (from the recent EU regulation on data protection 'GDPR' [23] point of view) and their responsibility to ensure the availability of data for the progress of research and for the healthcare systems' improvements. On point *a* 'All health-related data is owned by the citizen', some respondents underlined the risk related to an excessive individualization of data ownership such as the individual monetization of data currently proposed by several commercial platforms.

Regarding the implementation of Perspective 1, a majority of respondents (61%) declare that it is not a reality in their geography and its achievement is still below 30%, but half of them (50%) believe that it will be fully implemented between now and 2030 (20% did not answer the question). The participants indicated a series of steps requested for the full implementation of Perspective 1 such as the design of user-friendly and interoperable solutions and infrastructure for data collection and data access, the emergence of innovative models for data governance,

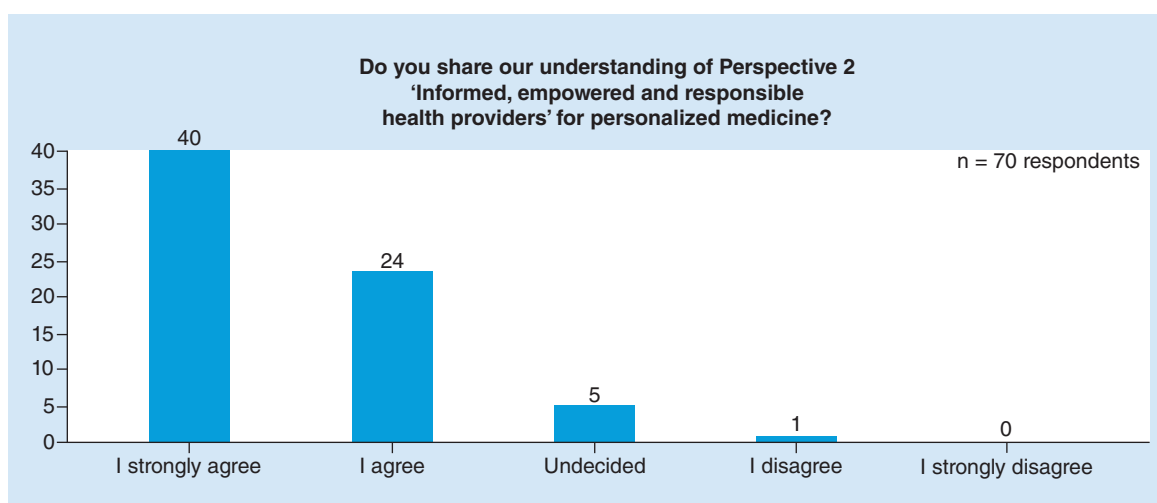


Figure 4. Levels of experts' agreement with Perspective 2.

the development of educational and training programs both for citizens and professionals, along with voluntarist public policies at all levels (European, national and regional). Finally, several examples of best practices [16] have been suggested by the respondents around the topics developed in Perspective 1.

Perspective 2: 'Informed, empowered & responsible health providers'

Perspective 2 'Informed, empowered and responsible health providers' benefited as well as Perspective 1 from a large approval by the experts: 91% agreed or strongly agreed with the suggested definition (Figure 4). Fewer respondents decided to comment this perspective and their remarks were related to the reinforcement of the education of health professionals but also their engagement in PM approaches. Remarks on the wording of the statement were that it should read 'engaged' rather than 'empowered' and 'accountable' rather than 'responsible'. Some participants pointed out the link between the purpose of Perspective 2 and the global framework of healthcare systems, and so the interdependencies between its propositions and the political decisions. Some respondents mentioned as well the need for better relations and collaborative work between research institutions and healthcare providers, in particular in terms of generation and dissemination of evidence from PM interventions. Education of healthcare professionals in the field of PM should incorporate both scientific tools like -omics technologies and digital literacy and it was suggested to include this as part of medical education to bring PM into standard of care.

The commitment of PM to disease prevention and as novel method of diagnosis in terms of molecular stratification of health/pathology was discussed beyond the application of PM to treatment. Access to robust datasets for evidence and support from multidisciplinary decision systems for clinical decisions were highlighted.

Again, a majority of experts (54%) believe that the implementation of such a perspective is still under 30%, but is pretty optimistic in the same proportion (54%) that Perspective 2 will be fully implemented in its geography by 2030 (21% did not answer the question).

Essential next steps mentioned by the respondents are related to the reinforcement of education of health professionals and medical training around PM and in favor of interdisciplinarity (creating new specializations or curricula in existing education system), the need for more researchers in order to generate and disseminate more evidences, the availability and investment in new generation of ICT tools to practice PM in healthcare settings and easier availability of data through shared infrastructures. The experts underlined again the central role of policy-makers in the definition of PM-oriented policies, as well as better regulation frameworks and guidelines and new economic models (such as value-based models). Several best practices [9] have been reported by the participants.

Perspective 3: 'Health systems enabling personally tailored & valuable treatment & prevention'

Ninety-three percent of the experts strongly agree or agree with Perspective 3 'Health systems enabling personally tailored and valuable treatment and prevention' (Figure 5). This massive approval is reflected in the comments around this perspective, as only 30% of the experts chose to add or omit elements to the proposition. These comments were

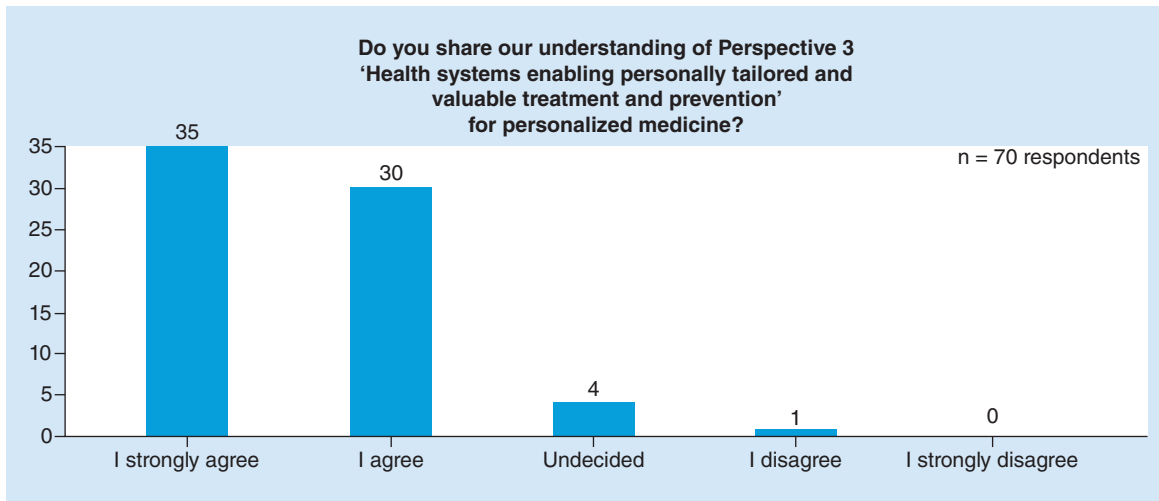


Figure 5. Levels of experts' agreement with Perspective 3.

mainly related to a clearer/sharper definition of the proposed subsections. Two words were specifically questioned: the word 'residence' as it was suggested that medical tourism would enable clinical research-based evidence for PM, and the word 'fair' for which respondents suggested to replace it by 'equitable'. There was a suggestion to add a note on tailoring health promotion and diagnosis in this section.

The estimation of current progress of implementation of this perspective is a bit more optimistic than for the previous perspectives, as 46% of the respondents believe implementation of Perspective 3 is more advanced with a progress evaluated between 40 and 70% of the full implementation and only 41% of respondents believe Perspective 3 is implemented between 0 and 30% in their geography. Globally, 56% of the participants believe that it will be fully implemented by 2030 (20% did not answer the question).

The experts are mentioning as requested next steps the need for a redesign or a reform of current healthcare systems, in particular around their financing and organizational models, and toward an orientation to more preventive approaches. The respondents mentioned as well the need for more support of research, and in particular independent research (supported by the public sector) and the connection between healthcare systems and clinical and biomedical research findings. They also underlined some common topics as for the previous perspectives such as the education of health professionals, the availability of data, related ICT tools and interoperable infrastructure and the political voluntarism in favor of implementation of PM practices. Seventeen best practices have been described by the experts.

Perspective 4: 'Health-related information/data are available for valuable treatment, care, prevention & research'

As for the other perspectives, Perspective 4 has been predominantly approved by the experts with 87% of them agreeing or strongly agreeing (Figure 6). Twenty-eight experts only reported some comments. Some are related to a broader definition of usable data such as adding omics, lifestyle, environmental or socioeconomic data, other experts are pointing out that the fact that including genome data within the EHR could be controversial.

Two-thirds of the respondents believe that the progress of this perspective in their geography is still under 30%, and half of them (50%) foresee its full achievement by 2030 (21% did not answer the question). According to the experts, the main steps for success are the creation of standardized and interoperable tools to store and share data (EHR, health platforms, genome centres, registries, etc.) associated with strong IT infrastructure. As for the previous perspectives, the needs of political perspective and actions and of a strong support of research in PM are underlined by the respondents. Seventeen best practices have been reported by the experts.

Perspective 5: 'Economic value by establishing the next generation of medicine'

Perspective 5 has been supported by 75% of the respondents (agreeing or strongly agreeing; Figure 7). Nevertheless, more comments have been expressed in order to disagree (13% of the respondents) or complement the proposed wording.

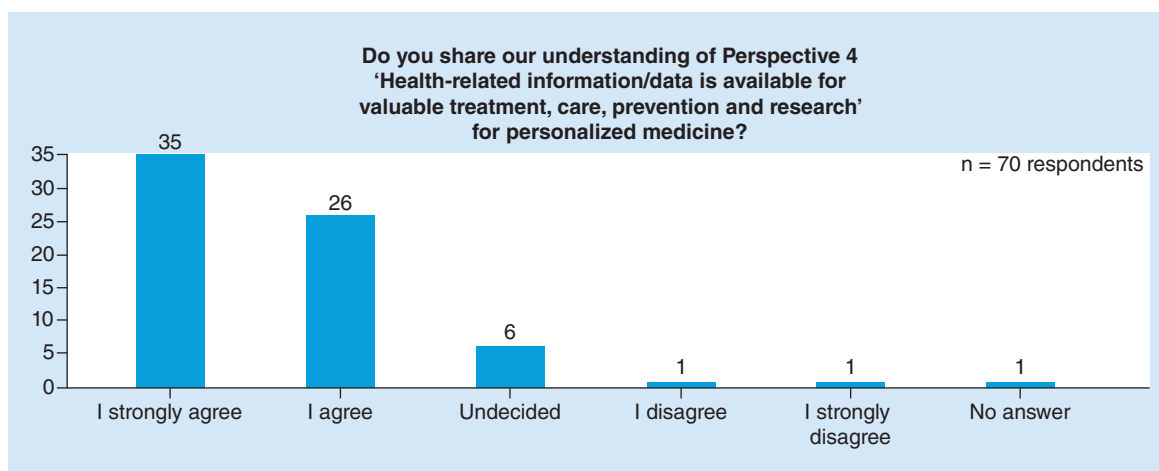


Figure 6. Levels of experts' agreement with Perspective 4.

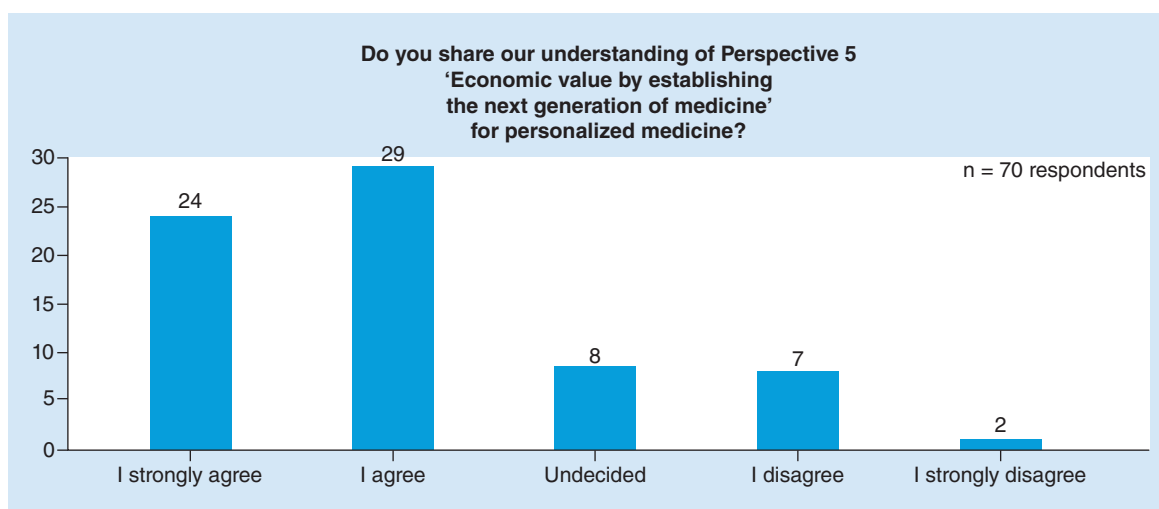


Figure 7. Levels of experts' agreement with Perspective 5.

Eight comments pointed out the danger of the emergence of a 'business-driven' healthcare. The experts highlighted the need to favor efficiency and quality of care rather than economic gains. They also stressed the importance to describe precisely the evaluation perimeter of the economic impact of PM, which could be global or societal rather than intervention-specific at the individual level. Several comments advocated for a better definition of this Perspective 5, questioning some of the terms and the completion of some of the proposed sentences.

A large majority (63%) of the experts estimates that the achievement of this perspective in their geography is under 30%. Less than the half (46%) believe that Perspective 5 will be fully realized by 2030, and the majority estimates that the implementation is a long-term goal to be achieved by 2035 (56%) or even 2040 (66%) (21% did not answer the question). The next steps indicated as priorities by the experts are related to the investments and budget allocation by decision-makers to PM research and deployment in healthcare settings. The respondents stressed the need for more research around the economic impact and value of PM. As for other perspectives, the experts stressed the fact that all efforts should be supported by voluntarist public policies, educational and training programs, interoperable ICT tools and multidisciplinary work. Ten best practices have been reported by the experts.

The last part of the questionnaire was proposed to the experts for the expression of their overall perspectives of the steps needed at an European level to develop PM in the upcoming 10 years. The experts mentioned six key areas:

- The need for further research and robust evidence for PM
- The need for educational and training programs for both citizens and healthcare professionals and providers
- The need for transnational cooperation and cross-border exchanges and interoperability for data
- The need for voluntarist public policies and a political agenda across Europe developing new common regulations, definitions of concepts and guidelines
- The need for innovative systems for data management (collection, storage, access control, sharing) at the EU level and the associated need for new technologies and IT infrastructures
- The need for massive investments and new financing (or reimbursement) models for PM in healthcare systems in Europe

Discussion/conclusion

In conclusion, the survey conducted by ICPeMed Secretariat with international PM experts has demonstrated a large consensus around the five perspectives defined by the ICPeMed's Executive Committee. The 97 experts who answered the questionnaire have approved in majority each of the perspectives, bringing in constructive comments in order to clarify some of the terms or to strengthen or specify the content of the propositions. As an example, we have noted that the term 'citizen' has been discussed by many of the respondents, as its definition could vary and designate various groups of individuals (inhabitant of a city, resident in a member state or a simple user of the healthcare system). For the purpose of this survey 'citizen' refers in a general manner to an individual.

We also need to mention several aspects here that have potentially influenced the results. First, the selection of the experts invited to the ICPeMed conference, who were as well the recipients of this survey, has been conducted by the ICPeMed's Executive Committee along predefined clusters of expertise needed reflected by the ICPeMed challenge groups and balanced by the ICPeMed Secretariat for gender and geography. We need to note here that given that the ICPeMed's Executive Committee has selected the experts involved in this survey, the selection might have been done within professional networks and communities, mainly from natural sciences and less from social sciences, and so presenting similar thinking and vision about the PM future development. This could explain a part of the result, which is a significant approval of the perspectives proposed by the ICPeMed's Executive Committee. We should note as well that the number of experts from the industry sector is limited (11%) but this is explained by the proper nature of ICPeMed's consortium and its objectives of looking for neutrality and balance between public institutions, research organizations and industry. Thus, the ICPeMed vision differs from existing pure industry-led vision statements about PM.

Second, the proper methodology used for the questionnaire's design could have generated some influence on the results such as the 'acquiescence response bias' [24], which shows that, in general, people who answer surveys like to be seen as agreeable. The long series of questions could also generate a phenomenon of 'straight-lining' [25], when a respondent moves down a series of statements too quickly, selecting the same answer choice for all.

Even if the total number of respondents could appear low, this survey has nevertheless been the opportunity to collect the perspectives of experts involved in the development of PM for several years and who will certainly shape the strategies and initiatives in the upcoming years. Each perspective has presented different aspects of PM development, but we can observe that the main next steps proposed by the experts are similar for the four topics: the presence of voluntarist public policies and political strategies in favor of PM; the development of platforms, IT tools enabling the data collection, control and sharing at large scale with a cross-border interoperability [26–28]; the need for large-scale educational and training programs both for citizens and for the healthcare professionals and providers; and finally the redesign of our healthcare systems in order to adapt to the new paradigm of PM, both in terms of organization of the system and equipment in healthcare settings and around the business cases and financing models used in the healthcare sector [29,30]. The experts stressed the concept of prevention and value-based healthcare, and the availability of clear scientific evidences, as key enablers of the full achievement of the perspectives.

In the future, it might be interesting to analyze, measure and compare the progress in the implementation of PM in different countries, in order to understand which are the most advanced nations. This work would tangible measurements and indicators whereas the purpose of the present survey has only been to collect the perceptions of international experts about the future development of PM. This additional research work might be a future task handled by the ICPeMed initiative and/or the authors of this article.

This survey has fed the work of the ICPeMed during the conference in Berlin in November 2018, but also the working group in charge to describe ICPeMed's vision paper called 'The ICPeMed vision for 2030 – How can

personalized approaches pave the way to the Next Generation Medicine?'. It is expected that the ICPeMed's vision influences in first place its members (national and regional ministries, public and private 'not-for-profit' health research funding and policy organizations) and more generally the next public policies and directives defined at three different levels, European, national and regional levels. This survey and the associated 'Vision 2030' paper aim also to have impact internationally beyond Europe through the ICPeMed global network. The uniqueness of ICPeMed, gathering more than 40 ministries and funders of health research across the world, make it the main forum to shape future decisions on research and implementation of PM.

Summary points

The article presents the results of a survey, realized by the International Consortium ICPeMed, with experts about the future of personalized medicine (PM). The four main recommendations for the deployment of PM, addressed to ICPeMed members (including ministries, public bodies and funding agencies), are:

- The presence of voluntarist public policies and political strategies in favor of PM.
- The development of platforms and IT tools enabling data collection, control and sharing at large scale with a cross-border interoperability.
- The need for large-scale educational and training programs both for citizens and for the healthcare professionals and providers.
- The redesign of our healthcare systems in order to adapt to the new paradigm of PM, both in terms of organization of the system and equipment in healthcare settings and around the business cases and financing models used in the healthcare sector.

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