Personalised Medicine Stakeholder Community

Following the Member States consultation by the European Commission, EP PerMed will be an opportunity to bring together all stakeholders of the Personalised Medicine (PM) value chain.

Stakeholders can be industry, universities, research organisations, bodies with a public service mission at local, regional, national or international level or civil society organisations including foundations and NGOs (*Article 2 of the Horizon Europe Regulation*). Existing networks from the ICPerMed, ERA PerMed and the ICPerMed CSA Family could provide the basis for building this Partnership which will create the synergies needed for the integration of all essential expertise in PM from the Stakeholder community.

The diversity of the national and regional healthcare systems and funding structures makes convergence difficult, but this European Partnership (EP) will be inclusive and encourage the participation from all European countries and international organisations from different continents, including countries with small research communities and different advancements in PM. Different organisations might join it as EP PerMed MEMBERS or as EP PerMed PARTNERS. The **EP PerMed MEMBERS**, by signing the Grant Agreement (GA), should work to form the partnership and work actively towards achieving the overall aims of the EP. They will undertake the commitment of a dedicated budget and will be eligible to receive reimbursements. The **EP PerMed PARTNERS**, by signing a letter of intent, should monitor and support the different procedural steps and initiatives, without any financial commitment and without any financial support. While it is suggested by ICPerMed and ERA PerMed that the member and partner status within the EP PerMed is restricted to ministries, public and private 'not-for-profit' health research funding, policy organisations and healthcare institutions, other stakeholders with strong interest in PM could be welcome to participate via dedicated stakeholder groups with observer status.

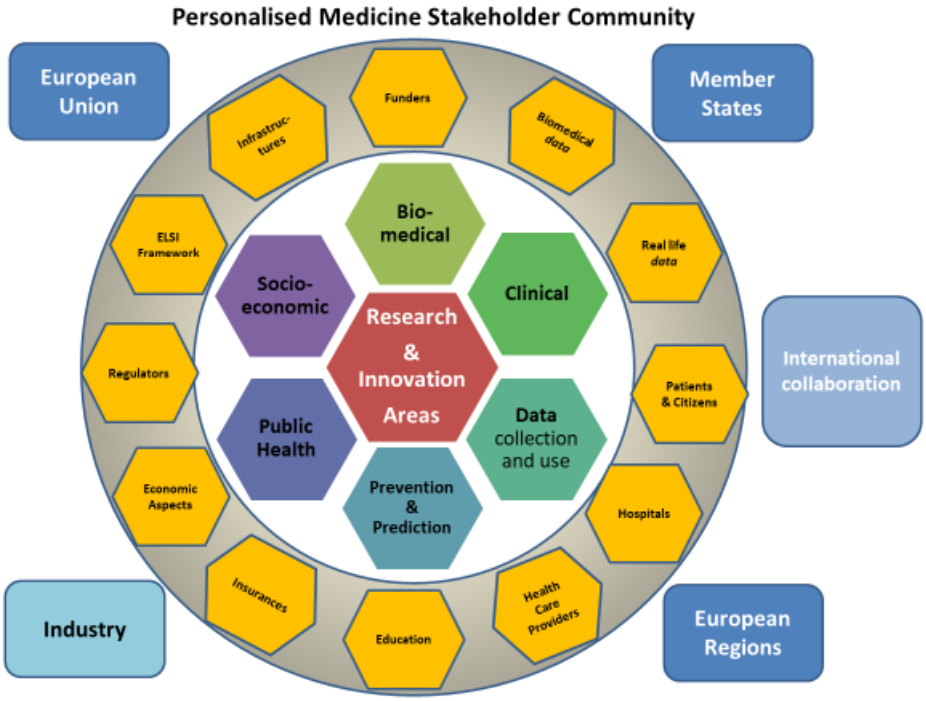
ICPerMed and ERA PerMed suggest that this so-called stakeholder community needs to be involved from the start phase and will be crucial as support for the successful development and implementation of PM approaches. They should be able to collaborate from the identification of challenges and opportunities to the alignment on regional, national, European and international levels with complementary access to resources, information and data. Indeed, the participation's benefits can be for:

- ✓ **Researchers** across European countries and regions could enhance collaborative research on PM and achieve transnational collaborations in research funding; **International collaboration** can consolidate the research beyond the EU;
- ✓ **Health and care authorities, policymakers** and other stakeholders could develop evidence-based strategies and policies on PM and learn from good practices on PM of European countries and regions, but also of non-European countries; achieving alignments on the strategic level as well as the increasing of resources and could apply new strategies on how to plan and carry out efficient investments in PM at national/regional level;
- ✓ **Researchers, policymakers and other stakeholders** should use widely-disseminated research results based on Open Science principles; **Citizens and health and care professionals** could increase their PM literacy to better understand and apply PM approaches;
- ✓ **Healthcare providers and professionals** should be facilitated to increase their knowledge on how to implement PM approaches;
- ✓ **Innovators and all types of local/regional private stakeholders** could join together and this might facilitate the uptake of successful innovations;

- ✓ **Patients, citizens and society** as whole could participate and play an active role in the PM implementation

Ideally, the cooperation of all stakeholders might facilitate consensus-building and decision-making processes in the PM implementation of the research outcome into the health systems with respect to upcoming needs.

The role of every actor may be based on their functional role such as policy, funding research, support activities or consultation. ICPerMed and ERA PerMed suggest the **involvement of different kind of organisations as members, partners or stakeholders**, to achieve a flexible framework for cooperation and efficient execution of the proposed work programme at the operational level.



General overview of the personalised medicine community: Research and innovation (R&I) are the key elements in the very centre that are influencing and driving the development of PM approaches. Areas of R&I, essential as support and basis for the successful development and implementation of PM approaches, are represented in this figure, in the inner circle. In the outer (grey) circle, the major stakeholders for the PM environment are shown, that are developing and monitoring and supporting R&I leading to PM implementation for patients and citizens. The decision makers (blue frames) are in the position to set important impulses in terms of funding, frameworks, infrastructures, and regulations

This Information Sheet is the result of ICPerMed/ERA PerMed reflections on EP PerMed aspects. The concept, legal and financial frameworks for the EP PerMed are still under development (e.g. governance, partner/member/stakeholder rules for participation, etc.), and the Information Sheet will be adapted in the future to integrate and outline such technical aspects when relevant. The Information Sheet received valuable input from the European Commission (EC) but does not represent an official EC document.

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