IC2PerMed Working Groups

Working Group 1
Shaping sustainable healthcare

This WG’s activities focus on awareness and empowerment of citizens and patients, education and curricula of healthcare professionals, and healthcare sustainability. For PM to be routinely implemented in clinical and public health practice, both patients and health professionals should be aware of the possibilities offered and how to make the most of them.

Given the need for informed, empowered, engaged and responsible citizens, there is a need to deepen digital literacy, knowledge of health data, public trust in institutions and easily accessible, reliable and understandable sources of medical information. Informed, accountable and empowered health service providers are also essential. The safe, responsible and optimal use of health information and research results required for PM should be routine in clinical settings. Clinical decisions should go through multidisciplinary teams, integrating new health professions. Clinicians and researchers, and all relevant stakeholders, should work closely together to support the rapid development and implementation of PM solutions.

The considerable global burden of non-communicable diseases and limited healthcare resources put the spotlight on the need for health systems to be sustainable. The careful use of resources, with prioritised allocation and equity, to ensure the translation of innovation and value, enables personalised and optimised health promotion and disease prevention, diagnosis and treatment for the benefit of patients. To foster the adoption of new policies, following the public health policy cycle could be extremely helpful.

A citizen- and patient-centred approach is required to provide guidance to researchers and developers. Health budget constraints must be considered early on, and novel reimbursement measures are potentially necessary where cost-effectiveness is an issue. Innovations on personalized prevention measures in particular demand a holistic view on budget and should not be limited to healthcare.

Working Group 2
Innovation and market

This WG’s activities focus on Big Data and ICT solutions and on bringing innovation to market.

Big Data refers to datasets that are unprecedented in size and complexity, made possible by recent advances in automated collection of large-scale molecular and clinical data and the creation of new, increasingly powerful, computational approaches requiring novel ICT solutions. Big Data raises several issues for public policy makers, including personal data ownership and protection, skill gaps in labour markets and an emerging new digital divide. Hence, policies in this field are fundamental for the regulation of these aspects. Besides this prime example of disruptive innovation in the context of Big Data, the innovation ecosystem is similarly important to translating basic research and innovation progress into PM solutions in the hands of end users and eventually patients and citizens. The working group highlighted the importance of targeted innovation incentives tightly linked to questions of research and innovation funding. Besides prioritizing and supporting financially crucial PM, Technologies and infrastructures with adequate budget, the long-term perspective on market adoption and uptake of new approaches is central to bringing innovation to market.

Working Group 3
Research and clinical studies in PM

This WG’s activities focus on translating basic clinical research and beyond, and on research funding. In order for PM to reach its anticipated impact on human health and wellbeing, translation of discoveries and communication across the continuum of research is required. This starts with the integration of all ‘-omics’ data to generate and implement meaningful interventions. Such processes should be supported by reclassifying diseases at the molecular level and by developing preclinical models to validate hypotheses resulting from molecular analyses. A Europe-wide process to evaluate and validate biomarkers, together with longitudinal and in-depth studies to further characterise diseases and their progression would support ongoing efforts towards this integration and re-classification. The development of new clinical trial designs that are adapted to these new approaches and the integration of preclinical testing with innovative clinical trials may further improve the effectiveness of interventions.

Collaborative pre-competitive and trans-disciplinary research and cross-sector collaborations need to be promoted and supported by suitable funding mechanisms, in order to truly bridge all steps of the PM research continuum.

This project has received funding from the Chinese MOST Intergovernmental Project of National Key R&D programme under grant No2021YFE0192400.
IC2PerMed actions

Based on the activities of WP1 and WP2, the IC2PerMed consortium developed a Roadmap which presents the main topics and priorities that emerged during the discussions held within the project. This document aims to propose, through the actions listed below, the items to deepen and promote alignment and creation of a common ground for European and Chinese collaborations on PM.

**IMPROVING EMPOWERED AND RESPONSIBLE CITIZENS**

Promoting health literacy is a prerequisite for better citizens’ and patients’ engagement and empowerment. Considering the emergence of digital technologies and the role of digital tools in supporting the engagement process, digital literacy should be improved. Given the advancement of genomics and the widespread use of predictive genetic/gene testing, informing citizens and patients could provide them with greater awareness about their health trajectories. The impact of healthcare professionals’ literacy should be considered, as they are a proxy for public engagement in self-management of patients’ health.

**PROMOTING TRAINED AND UP-TO-DATE HEALTHCARE WORKFORCE**

Improving healthcare professionals’ literacy and expertise, valuing integrity and ethics, could help foster PM. Research aimed at identifying methods that are more effective should be promoted.

**EDUCATION & ETHICS**

The future of healthcare professionals training relies on multidisciplinary collaborations. Fostering collaborations between professionals from different specialties and between professionals and stakeholders, while establishing more partnerships among countries, to facilitate sharing of best practice.

**COLLABORATIONS**

Healthcare professionals’ literacy in Personalised Medicine is an emerging priority in national governmental strategies, policies and plans.

**POLICIES**

Ethical, Legal and Social Implications (ELSI) aspects and related costs should always be considered in the process of Personalised Medicine policymaking, evaluation, and management of technological innovation.

**RESOURCES**

A better allocation of resources on PM can foster the sustainability of health systems. In particular, the identification of a large investment stream for the long-term storage of data is a fundamental prerequisite for implementing PM strategies.

**NETWORKS**

Multidisciplinary and cross-sectoral collaborations for PM can promote the sustainability of health systems. Public-private partnerships and international networks should be valued for sharing experience, and for promoting and evaluating best practice and progress in PM.

**FOSTERING HEALTHCARE SYSTEMS’ SUSTAINABILITY**

Health technologies are evolving rapidly and the translation of new discoveries underpins innovation and quality of care. Therefore, a system of continuous assessment of technologies and processes already in use and a change of perspective in Health Technology Assessment (HTA) is needed to integrate end-user perceptions into the whole innovation process. This would ensure greater effectiveness and usefulness.
The application of personalised diagnostics and therapeutics should be geared towards lowering economic costs and barriers to market uptake. With regard to diagnostics, promoting research in PM aimed at a more appropriate use of diagnostic tools (avoiding overuse, overdiagnosis and overtreatment) could lead to an optimal use of resources in the field of prevention and consequently an increase in the value of healthcare. Health insurance providers should extend their coverage to innovative and high-value PM solutions and reimbursement of services should be promoted or attempts should be made to reduce barriers to reimbursement. In implementation processes, economic, cost-effectiveness and relative value analyses should take into account both social and health budgets as well as non-optimal resource use in the system.

New solutions on the market must put the emphasis on maximising health outcomes for patients. An early, intensive, coordinated and continuous dialogue between all PM stakeholders involved is needed. The various PM actors should follow a set of shared principles and universal guidelines on data sharing and exchange. Innovations that aim to effectively combine data from different sources (genetics, clinical data) and regions, focusing on their standardization for effective usage. Standards for data use should be adopted and implemented, also with a view to establishing common policies and global efforts for cross-border data sharing.  

In the field of PM, it is essential to study solutions aimed at effectively combining data from different sources (genetics, clinical data) and regions, focusing on their standardization for effective usage.

Funding agencies should tailor investments to the needs of patients. There is a need to promote the voice of patients (and caregivers) at all stages of PM research, from co-designing research projects to advisory roles and enhancing educational initiatives to improve the scientific literacy of patients and researchers. Defining unmet needs and potential incremental innovation could help in laying the groundwork for new international collaborations.

Investment plays an important role in the entire value chain and is needed from basic science to the implementation of PM in healthcare. Funders, both public and private, act as a first filter on the prioritisation of resource allocation, and this should be done responsibly. Furthermore, adequate investments are crucial in the research translation system.

Omics sciences are fundamental to the development of PM. Phenotyping patients, following defined standards, could identify similar patients. Besides genomics, applications of different omics sciences and technologies should be promoted and used for the identification of biomarkers suitable for PM. Innovative methods that have shown great promise in the field of PM, including the use of induced pluripotent stem cell and organ-on-chips, models should be evaluated and adopted, valuing international partnerships.

To promote international collaborations, especially on oncological care and rare diseases, it is important to support non-profit foundations and funding agencies. Establishing incentives and frameworks for public-private collaboration can facilitate academic and industrial access to biological samples and data for research purposes. It is necessary to facilitate and strengthen the dialogue with regulatory and HTA agencies, companies and academic entities to gain a clear vision in terms of outcomes researched, and to identify the most appropriate research methods to investigate PM both ensuring patient safety and adapting to the characteristics of study populations.

This project has received funding from the Chinese MOST Intergovernmental Project of National Key R&D programme grant No2021YFE0192400

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 874694