ICPerMed
INTERNATIONAL CONSORTIUM

Action Item Group 5 : People and Society

Actions

Action	Description
A.19	Research and develop the tools and modus operandi of a knowledge network for enhancing health and digital literacy
A.20	Develop and share best practices of patient engagement approaches for the need of a variety of European citizens
A.21	Research and develop the instruments for the evaluation of the effectiveness and impact of public engagement initiatives in PM
A.22	Support interdisciplinary research in challenges and drivers that influence bringing PM innovation to the market, from ethical, legal and societal perspectives
B.8	Build sustainable resources for educating and training citizens, patients and patient advocates on involvement of patients and patient organizations across the entire research and development lifecycle of personalized medicine

First activities of the Group

Contributing to the definition and collection of best practices

The idea behind this activity is to create a flow of communication for interchanging best practices that can foster the innovation that PM is bringing into healthcare systems.

Step 1: what is a "*best practice*"?
We will reach an agreement on the definition of "best practice", a procedure that has been shown by research and experience to produce optimal results and that is established or proposed as a standard suitable for widespread adoption.

Step 2: *how do we know* if a practice is indeed a *best practice*?
We are in the process of developing a simple tool that can be used by the group members to interrogate the stakeholders that have put best practices in place in their institutions. This tool should facilitate the collection of best practices in place in different countries, so that it can be used as example for other members of the ICPerMed consortium.

Reflecting on the implementation of society engagement strategies in PM

Patients and citizens can play a fundamental role in the identification of research questions, as well as study design, recruitment, data collection, and analysis of findings. We will study the most effective strategies to ensure that PM benefits are understood and shared by patients and citizens.

Next steps

We will continue our activities on Action B.8 of the Action Plan, which is mainly focused on the training and involvement of all the players in the PM field, especially patients and citizens. To this aim, we will at first:

◊ Collect information on initiatives where the lay public is already engaged and play a primary role.
◊ Develop a tool to explain the importance and the meaning of PM to the citizens, building on the previous experiences of AIG-5 Members (i.e. the booklet on PM realised by FRRB, frrb.it/it/news-mp)

Common activities

◊ Mapping activities on PM initiatives (in particular non-funding activities).
◊ Selecting the best practices that have been positively evaluated for the ICPerMed website.
◊ Suggesting topics for the ERAPERMED calls for projects in the PM field.
◊ Contributing to the ICPerMed state of the art report and in the implementation of the Action

Participants

Institution	Country
Fondazione Regionale per la Ricerca Biomedica	Italy
Portuguese National Institute of Health Doutor Ricardo Jorge	Portugal
Bundesministerium für Arbeit, Soziales, Gesundheit und Konsumentenschutz—Sektion VIII	Austria
Italian Ministry of Health	Italy
Health Research Board, Dublin	Ireland
Centre for Innovation in Medicine	Romania
ZonMw	The Netherlands
Ministry of Human Capacities	Hungary

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Contact information

Please contact the AIG-5 leaders or ICPerMed Secretariat and the AIG 5 Leader for any questions concerning AIG-5 and its activities.

E-Mails: icpermed@dlr.de; paola.bello@frrb.it; paola.larghi@frrb.it