ICPerMed
INTERNATIONAL CONSORTIUM

Workshop Summary

Plenary Session 4.2.

Madrid, 05.11.2019, Dr. Ulrike Busshoff

….informed consent is just not enough….we have to do better and build trust across sectors

- Research (academia & industry)
- Health Care Systems
- Society

Key issue is building trust of all stakeholders in PM research by

- Providing high quality, reproducible and interoperable data from multiple sources.
- Training scientists on PM trial methodology, data management & analysis (FAIR), regulatory pathways and patient involvement and patient needs (co-creation).
- Managing uncertainties in translation to real-world settings and fund independent clinical trials.
- Promoting the creation of a PM roadmap based on strong research agendas.

Build trust within health care systems and health policy decision-makers for PM approaches by

- Providing training for HCP, especially GPs, pharmacists and nurses.
- Planning for change at a systemic level with a step-wise approach.
- Creating a integrated PM pipeline adapted to regional/regional reality based on patient empowerment and effective participation of stakeholders.
- Providing evidence for feasibility of PM in up-scaling pilots to national roll-outs.
- ICPerMed providing a portfolio of success stories and serving as a forum for policy-makers from the health care domain.

Build trust within society for PM by

- Ensuring safe data and controlled access to data.
- Developing tailored education & literacy programs and trustworthy sources.
- Initiating adequate communication of scientific results by delivering on information needs of patients and citizens.
- Co-creating with the patient community and the public specific actions for PM interventions.
- Finding adequate solutions for access and equity.