

Personalized medicine: How to ensure awarness and empowerment for all citiziens?

Working Group I

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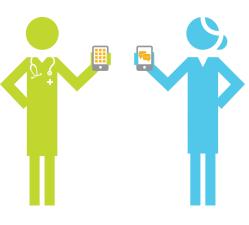
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Leading Question 1. Role of (digital) health literacy in patient empowerment

Leading Question 2. Transformation of the role of the patient towards the disease through data management

Leading Question 3. Patient and public engagement with their health services



- Map the existing tools and experiences
- Map the needs
- Improve understanding in Personalised Medicine in all the groups of healthcare professionals:
 - Nurses
 - Pharmacists
 - Physiotherapists
 - Physicians
- Using
 - o different channels
 - case studies
 - good experience across regions/countries



CHALLENGE: Engage at the national and local level. Involve communication experts.



To increase literacy:

- Trustworthy sources of information
- Online courses from trustworthy sources
- Involving patient advocacy groups
- Role of the physicians (specially GPs) having tools recognising trustable information
- Modernised patient information leaflets

CHALLENGE: Difficult to work at different levels with different messages



Importance of accessing data and generating data.

- Access to data
- Empowering policy makers on the relevance of digital determinats of health
- Digital health programs shouldn't be vertical, but integrated with the national health plans
- Establish and introduce PROMs and PREMs for personalised medicine
- Inform patients involed in clincial trials about the results

CHALLENGE: implementation of the EU recommendations (incl. Interoperability) at national/regional/municipality level. Use the existing policy initiatives such as health data space.



Patient and public engagement with their health services (building trust)

- Communication among patients (building social networking)
- Patient advocacy groups as peer groups
- IC PerMed examples/projects → help building trust and better communicate scientific results
- Personalised medicine public health

CHALLENGES: Training of the patient advocacy groups; language barriers; choose the benefiits to be communicated