

Personalized medicine: How to ensure awareness and empowerment for all citizens?

Working Group I

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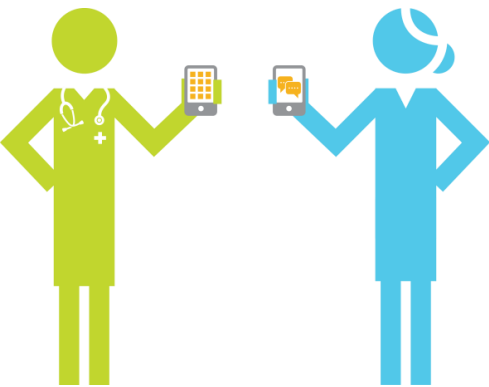
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Personalized medicine: How to ensure awareness and empowerment for all citizens?



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

People to be on board have to know what they are talking about, and understand that there is a lot of work that can be done to increase literacy:

- Online courses available that can be relayed on
- Involving patient advocacy groups
- Role of the physicians (specially GPs) having tools recognise trustable information
- Patient information leaflet (EMA ongoing)

CHALLENGE: Difficult to work at all those different levels

Lack of understanding in Personalized Medicine in all the groups involved:

- Nurses
- Pharmacists
- Patients
- Physicians



Need to use all the different channels to train all those groups in Personalised Medicine. Use of case studies to educate considering that we cannot have the same solutions in the same countries

CHALLENGE: Engage at the national and local level

Importance of accessing data and generating data.

- Establishing indicator patient relevant outcome.
- Inform patients involved in clinical trials in the output of the trials
- Empowering policy makers on the relevance of digital determinants of health
- Digital health programs shouldn't be vertical, but integrated with the national health plans.

CHALLENGE: Interoperability and implementation of the EU recommendations at national/regional/local level

Building the public trust

Communication among patients (building social networking)

Patient advocacy groups as peer in the countries to get closer to the public.

IC PerMed can provide examples, projects → help building trust and better communicate scientific results

Personalised prevention should be the firsts area to be tackled

CHALLENGES: Training of the patient advocacy groups; language barriers; difficult to communicate the benefits when only 20% of population would potentially benefit of Personalised Medicine treatment