

PERSONALISED MEDICINE: "CITIZENS' PERSPECTIVE AND NEEDS"

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“ A STRONG PATIENTS' VOICE TO
DRIVE BETTER HEALTH IN EUROPE ”



PM is part of patient-centred healthcare

- Tailored healthcare solutions integrated as part of a *holistic approach* – treating the person, not the disease
- Promise: better health outcomes, quality of life and cost-effectiveness of resource use
- Terminology? Some EPF members prefer "precision"/"stratified" medicine, or "targeted therapies"

Principles of patient-centred healthcare (IAPO):

1. *Respect* for patients' unique needs, preferences, autonomy
2. *Choice* of appropriate treatment option that best fits patients' needs
3. *Patient empowerment* and involvement in decisions that concern their health
4. *Access* to safe, high-quality, appropriate services and support
5. *Information* that is reliable, relevant and understandable
6. *Patient involvement* in health policy to ensure services are designed with the patient at the centre

Challenges of personalised medicine

As well as promise and hope, PM also presents questions and challenges for patients:

- Timely and equitable access without discrimination
- Making effective use of health data while addressing potential risks
- Patient empowerment and relationship with health professionals
- Health literacy – access to accurate, up-to-date, unbiased information
- Patient organisations as integral actors at all levels & stages



Access and equity – a fundamental concern

- Healthcare must be based on the fundamental values of equity and solidarity – but currently huge disparities in access *to even basic healthcare*
- Innovative treatments tend to be costly – while governments are under pressure to cut costs
- PM should contribute towards equitable access and towards addressing unmet medical needs – need for patient involvement in R&D from the outset
- Needed: a common way of assessing added-value of Innovative treatments – e.g. HTA – valuable innovation should be accessible to all patients, not only those who can pay
- Cost-benefit assessment must consider quality of life – need for patient involvement across the "access chain", particularly HTA



Patient data – achieving the right balance

Sharing of health data is of vital importance for research

Patients' health/genetic data are sensitive – concerns about discrimination or negative consequences of inappropriate disclosure

Basic principles:

- Patients are owners of their data; fundamental right to access one's own data and control its use
- Meaningful informed consent is crucial to ensure patients understand how their data is used – same definition across EU
- Transparency, including for data from all clinical trials
- At European level, a proportionate, unified data protection framework that enables research and appropriate (re-)use of data, with the necessary safeguards to generate trust
- Cooperation on patient registries, biobanks etc.



The patient-professional relationship



- HCP need new skills on PM – how many GPs/specialists know about enough to discuss with patients?
- Shared decision-making is not “optional” but vital
 - Patient as *active and equal partner* in managing their condition
 - *Communication* in a way that respects individual patients' information needs and circumstances
 - Knowing how to *listen*, how to elicit patient's *preferences*
 - Work in a *team* with other professionals
- A **fundamental shift in medical culture**, professional and patient roles: from paternalistic/patronising to **partnership**
- **HCP education** and training, attitudes need to reflect this
 - Cross-EU HCP curriculum for patient empowerment
 - Cross-EU HCP curriculum on personalised medicine

Health literacy implications of PM

Today's paradox: people must make healthy choices and manage their health in a complex environment – but they are not well supported to do this.

- Many people in Europe have inadequate health literacy ([HLS-EU](#))
- Healthcare systems are not user-friendly, difficult to navigate even for the well-educated
- Scientific developments increasingly complex
- Information overload, mis- and disinformation (media, Dr Google...) and yet
- Lack of easy access to reliable, relevant and understandable information



Personalised medicine adds another layer of complexity to this picture!

The “information gap”

Patients want:

- comprehensive, accurate, unbiased information
- clear and simple explanations of complex concepts
- to understand how these relate to their own personal situation – so they can make informed choices
- no false hopes / unrealistic expectations

Patient advocates:

- are keen to advise researchers on patients’ priorities, trial design, information design, consent, ethics...
- are keen to give the patient perspective on policy, regulation...
- often lack the knowledge and confidence required to participate as equal partner in these debates

→ ***Need for capacity-building – e.g. through courses like EUPATI***

PerMed recommendations (i)

5. Health System also involving patients /public

- Promote models for individual ownership of personal health data
- Educate health professionals and provide funding for literacy in Personalised Medicine
- Educate health professionals in patient involvement
- Define Personalised Medicine and provide proof of concept within the health systems – so we all speak the same language – a common understanding and definition
- Develop a framework for pricing and reimbursement of Personalised Medicine that ensures equitable access for all patients – regardless economic or geographic status – and is sustainable for health systems

PerMed recommendations (ii)

6. Patients / public

- Develop communication and education strategies to increase patient and public awareness and health literacy – different target audiences with different needs – from expert patients to patient organisations and the wider public
- Incorporate patient participation in the healthcare ecosystem and increase their role in all phases of development – responsibility of all: companies, academia, regulators...
- Develop common principles and legal framework that enables sharing of patient-level data for research in a way that is ethical and acceptable to patients and public (see 5. above)

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Patient Empowerment is both a goal and a process

All patients with chronic diseases become ‘experts’ by virtue of being patients:

- Experts in living with their disease or condition every day
- Experts in knowing what works them, treatment-wise, and what does not.
- Because healthcare decisions ultimately affect patients, empowerment and involvement is their fundamental right.

This patient’s expertise needs to be recognised and embraced.



“You have to learn about thousands of diseases, but I only have to focus on fixing what’s wrong with ME! Now which one of us do you think is the expert?”