

10 PRINCIPLES FOR GREATER PATIENT EMPOWERMENT

Since the start of the COVID-19 pandemic and with health systems under more pressure than ever, patient disempowerment has been internationally recognised¹ as an overlooked but major healthcare challenge. Too often, patients are side-lined during discussions and decisions that affect them.

At both EU and national level, gaps in patient empowerment negatively affect people of all ages and backgrounds. More needs to be done to remove these longstanding barriers and **it is crucial that the voice of the patient is at the heart of the solution**. Directly involving patients in decision-making at all levels to ensure that they play an active role in their treatment and care pathway is a priority for public health, now more than ever.

Representatives from patient groups, civil society organisations, trade associations, and policymakers have produced a set of 10 principles and actions to support advocacy and awareness-raising around the importance of patient empowerment.

These principles specifically relate to the following three areas where patient empowerment is a key concern:



“THE COVID-19 OUTBREAK HAS EXPOSED AND EXACERBATED THE VULNERABILITY OF OUR HEALTHCARE SYSTEMS, INCLUDING THE UNEQUAL DISTRIBUTION OF ACCESS TO MEDICAL ASSISTANCE, SICKNESS PREVENTION AND HEALTH PROMOTION SERVICES.”

Donna Walsh, European Federation of Neurological Associations

“THE CORONAVIRUS PANDEMIC SHOULD ACT AS A JUMPING OFF POINT AND AN ENABLER OF ACTION AT EU LEVEL.”

MEP Sirpa Pietikäinen



HEALTH POLICY

PRINCIPLE 1:

Systematically include patients in policy-making processes for all legislation that will affect their lives, treatment or care.

Example:

Gathering patient input for impact assessments, policy development

PRINCIPLE 2:

Raise awareness of policy discussions and issues that impact patients.

Example:

Providing and promoting access to relevant resources and educational platforms.

PRINCIPLE 3:

Promote collaboration and knowledge-sharing to develop a clear, common focus.

Example:

Establishing shared health platforms or forums of benefit to all participants.

“THERE IS NOBODY WHO CAN DESCRIBE THEIR CONDITIONS OR NEEDS BETTER THAN THE PATIENTS THEMSELVES.”

Charis Girvalaki, European Cancer Patient Coalition

“WITH BIOSCIENCE AND DIGITAL TOOLS MOVING FAST, THE GAP BETWEEN SCIENTIFIC INNOVATION AND POLICY MAKING NEEDS TO BE CONSTANTLY NARROWED IN THE INTEREST OF PATIENTS. CONTINUOUS DIALOGUE IS NEEDED TO BETTER UNDERSTAND VALUE. WE KNOW THAT VALUE FOR ONE PATIENT ISN'T THE SAME AS VALUE FOR ANOTHER PATIENT.”

Violeta Georgieva, Europabio



RESEARCH & DEVELOPMENT

PRINCIPLE 4:

Better involve patients in the entire life-cycle of all innovative solutions.

Example:

Stimulating industry and patient collaboration from the outset.

PRINCIPLE 5:

Support a patient-driven approach to the digitalisation of R&D services.

Example:

Leveraging the virtualisation of clinical trials to diversify patient engagement and participation.

PRINCIPLE 6:

Effectively communicate clinical developments to foster access and awareness.

Example:

Implementing translational multi-disciplinary pathways.



ACCESS TO TREATMENT & CARE DELIVERY

PRINCIPLE 7:

Improve access to treatments, services and support, and reform patient care pathways by optimising the digitisation of healthcare in the EU.

Example:

Promoting more flexible regulatory approaches and approval procedures.

PRINCIPLE 8:

Prioritise data which reflects patient-reported experiences and outcomes.

Example:

Supporting the generation and use of robust real-world evidence.

PRINCIPLE 9:

Involve patients in regulatory and reimbursement frameworks and ensure transparency on how their input is used.

Example:

Ensuring patient representation in EU and national and regional HTA authorities.

PRINCIPLE 10:

Highlight the impact of socio-economic and demographic inequalities on health outcomes and disparities in treatment and care.

Example:

Undertaking studies into access inequality for vulnerable and disadvantaged groups and communities.

**“HEALTH IS
UNDER-RESOURCED IN
MANY MEMBER STATES.”**

MEP Sirpa Pietikäinen

PUTTING THE PRINCIPLES INTO PRACTICE

As governments and health systems continue to grapple with the pandemic, empowering patients demands collective, concrete action. These 10 principles should guide advocacy, campaigning and decision-making – but they are just a foundation. We greatly encourage further dialogue and ongoing input from other patient advocates, advocacy groups and all stakeholders interested in working together to empower patients everywhere.



In collaboration with



We would also like to thank MEP Sirpa Pietikäinen for her valuable input and support.

*International Alliance of Patients' Organization (IEEPO): Patient Care After COVID: Providers Must Correct 'One Size Fits All' Approach (2020), last consulted on 1 January 2021 at :<https://www.iapo.org.uk/es/news/2020/dec/22/patient-care-after-covid-providers-must-correct-%E2%80%98one-size-fits-all%E2%80%99-approach>

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