

Future Role of Patient Organizations in the Health Policy Decision-Making

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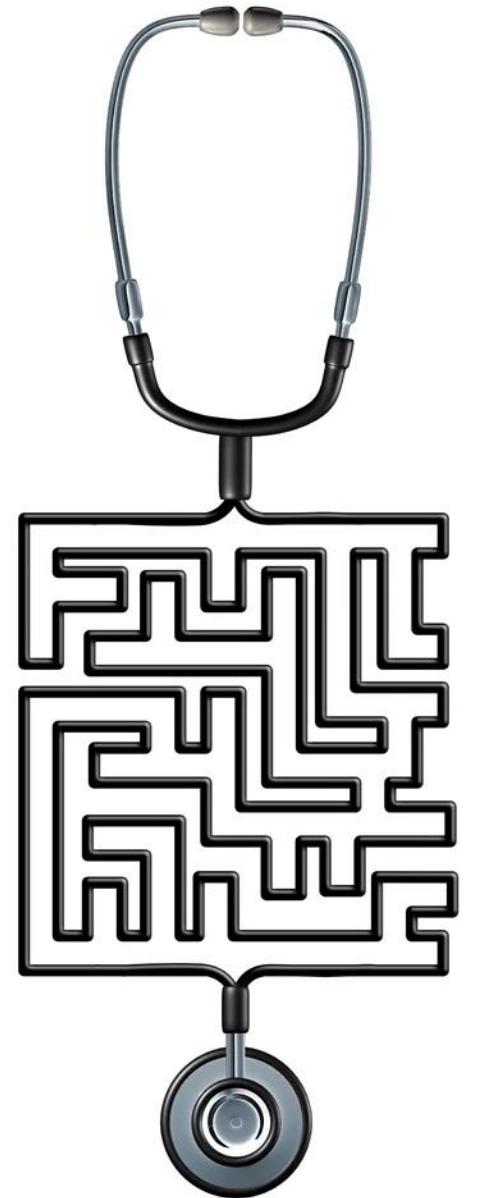


Policymakers

- Increasing demand
- Selective process
- Ways of source
- Ways of presentation to other stakeholders
- Low administrative capacity

Patient Organisations

- High demand – increasing responsibilities
- Ways to respond to all challenges
- Maintain representativeness
- Unsustainable funding models
- Expertise of patient leaders and representatives





Patients

- Digital preparedness of patients
- Digital health literacy
- Patient involvement in the longer term
- Patients-policymakers cooperation

Overview

- Key step to ensure patients' participation in shaping health policies is the development and enforcement of relevant legislations.
- Policy-makers should invest in regulations that focus on equal and meaningful participation of patient groups in health policy decision-making.
 - ✓ Development of online informational and monitoring systems.
- Increasing demand for patient expertise
 - Little or no investment
- The main barriers preventing patients to participate in health and healthcare decisions are:
 - Limited knowledge about the health system and health policies as well as lack of lobbying and advocacy skills.
 - ✓ Targeted interventions on these topics would be beneficial in increasing patient participation in every aspect of decision-making.





The Future: Digital Patient Organizations

- Based on real data and patient experience, more policies will be tested and verified
- Virtual experts, expertise and engagement with the patient
 - ✓ Through technology
 - ✓ Through AI and Big Data
- Development of trustworthy health data space, facilitating the collaboration between patients and their associations



Is the EU ready for this?

General Principles

- ✓ Participation
- ✓ Solidarity
- ✓ Mutual trust
- ✓ Sustainability
- ✓ Empowerment
- ✓ Accountability





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