

Call to action: Patient Organisations' Role in Health Policy-making

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A STRONG
PATIENTS'
VOICE
TO DRIVE
BETTER
HEALTH
IN EUROPE

Patient group involvement is still an uphill road

- Patient organisations are legitimate and essential stakeholders in health policy-making through their unique and ultimate legitimacy
 - we bring not only the lived patient experience but also the healthcare user experience

BUT

- Involvement and representation of patient organisations in health care policy remains overall low
 - Considerable variance between Member States
 - Tokenistic involvement of patient groups is still present

Key principles emerging from discussions today for strengthening patient organisations' role and contribution to policy making

- Political will
- Consultation and partnership
- Operational involvement
- Funding and sustainability

towards a truly participatory, democratic and impactful involvement of patient organisations

Political will

Strengthen **public participation** in national health policy design, implementation, and evaluation

Apply **key principles**: solidarity, mutual trust, sustainability, empowerment, and accountability



Consultation and partnership

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Consult patient organisations on appropriate channels and mechanisms for their meaningful and feasible participation

Operational involvement of patient organisations

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Involve patient organisations in the development of **health-impacting policies**, such as social affairs

Involve patient organisations proactively in **all stages of policy development**, including evaluation

Include patient organisations in **Health Technology Assessment** processes as equal stakeholders

Involve patient organisations in **operational** councils, specialized and/or sectoral committees or working groups

Funding and sustainability

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Support patient organisations' representative functions and role through **operational funding** and helping to identify a sustainable funding base

Impactful participation

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Promote truly participatory and democratic involvement of patient organisations by formalising the participatory processes and diversifying opportunities for participation

Principles emerging from the conference

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