IFPA
FORUM
EUROPE 2022

Theme 4

Involving patients and their organizations in decision-making processes

Psoriatic disease is an autoimmune disease that includes two specific inflammatory conditions. The two conditions, psoriasis, and psoriatic arthritis, result from an overactive immune system.

Globally, there is a need for patient involvement in policy development and decision-making. Quality care requires that people living with a disease are actively involved in all decision-making that eventually impacts how they live with and manage their condition. Involving people with psoriatic disease in decision-making can improve patient experiences and outcomes.

What is at stake?

Healthcare policymakers in Europe, including regulators and international organizations such as World Health Organization (WHO), are increasingly calling for patient involvement in decision-making processes[1]. Making patients an integral part of these processes and ensuring their participation is fundamental to realizing the core concepts of patient-centred care and empowerment[2-4]. Patient participation encompasses a broad range of activities from policy input to the planning, development, and implementation of health care programs, interventions, and services.

Patient organizations in Europe are a legitimate and invaluable voice in the civil dialogue on health-related policies and bringing the patient perspective to the decision-making table. They facilitate participation and provide input in a myriad of ways. At the policy level, for example, they actively participate through channels such as stakeholder advisory groups, expert panels, European and/or national government public consultations, or institutional meetings[2].

These organizations are also great advocators for increased patient involvement in different stages of the regulatory cycle of a medicine, from pre-submission and evaluation through to post-authorization, as well as Healthcare Technology Assessments (HTAs)[1]. They also have a crucial role in translating or

About the thematic briefs

The 2022 IFPA Forum will bring together stakeholders from the psoriatic community to develop a roadmap for action and promote regional uptake and implementation of the recommendations put forward in the WHO Global Report on Psoriasis. The Forum discussion will discuss the most pressing unmet needs of people with psoriatic disease and the quality of care. It will be structured around the following five themes:

- **Psoriatic disease, mental health, stigma, and quality of life**
- **Health workforce**
- **Access to early diagnosis, proper treatment, and financing for psoriatic disease**
- **Involving patients and patient organisations in decision-making processes**
- **Digital transformation and telemedicine**

interpreting complex information or policy processes and help patients navigate the complexity of the regulatory environment[4]. In recent years, patient organizations have also become better capacitated to contribute to regulatory and HTA decision-making effectively[4,5]. The fact that they are better informed, educated, and trained to focus on their patients' experiences has enabled the shift[5].

Policy and practice in Europe

Generally, there are many patient organizations representing people living with chronic conditions across Europe, but the lack of resources and funding is an ongoing problem in all areas of their work[4]. Furthermore, there is a systemic failure of cooperation and culture and tradition of tokenism when it comes to working with patient organisations[4]. A regulated and coherent legislative space that would ensure a right of access to independent, timely and adequate resources is also missing at the European level[4]. This means that the contribution of patient organisations to health and society in Europe could potentially be more significant than it is today.

Incorporating patient-reported and patient-relevant outcomes is necessary to determine a medicine's added value[4,6]. Patient organization participation can also ensure that HTA agencies are aligned with the end-user[5]. Patient advocates and patient organizations share common interests and goals with HTA agencies of improved access and affordability of health technologies, which can benefit from including patients and working in partnership[5]. Further, patient organizations help navigate the complexities of the regulatory process for medicines and raise awareness within the pharmaceutical industry.

The participation and empowerment of citizens and patients need to be regarded as a core value in all health-related work in Europe[3]. Patient organizations could consider ways to educate external stakeholders about what they do, the added value they bring, and why and how they work with industry partners[4]. Patient organizations should educate patient communities, the public and other stakeholders about patients' rights[4]. Patients have expectations, and they all want high-quality access to health care. Therefore, the dialogue with patient organizations and engaging them in defining goals and aspirations in health policy becomes even more critical.

Improving shared decision-making and patient involvement for a better outcome

1. Stakeholders should invest in meaningful patient involvement and work with patient organizations to develop and implement good practices, including compensation, facilitation/practical support, and capacity-building.

2. Researchers and academia/professional educators should systematically and actively involve patient groups in Research and Development (R&D) as joint grant holders, co-applicants, or members of project advisory boards or steering groups, particularly regarding research priorities.

3. Patient organizations' capacity to effectively represent patients' interests should be strengthened in a united and coherent way and give individuals a stronger voice to ensure their point of view is integrated at all levels of healthcare decision-making.

4. Policy-makers should invest in regulations that focus on equal and meaningful participation of patient groups in health policy decision-making. To this end, they should develop online informational and monitoring systems of patient groups in health policy decision-making. To this end, they should develop online informational and monitoring systems.

About IFPA

Founded in 1971, IFPA is the international federation of psoriatic disease associations. We are the psoriatic disease community. Our members represent over 60 million people living with psoriatic disease. Together, we advocate for progress.

Key takeaway

Encouraging patient organizations to participate in decision-making translates their insights into actionable solutions that help healthcare providers provide better healthcare for people with psoriatic disease. Existing tools for shared decision-making and principles that support higher levels of patient involvement should be leveraged to create a regulated patient involvement framework.

1. European Medicines Agency (EMA). Patients and consumers. Getting involved. Accessed June, 2022. https://www.ema.europa.eu/en/partners-networks/patients-consumers/getting-involved **2.** Souliotis K, Agapidaki E, Peppou LE, et al. Assessing patient organization participation in health policy: a comparative study in France and Italy. International Journal of Health Policy and Management. 2018;7(1):48

3. Bonsignore M, Brolis E, Ionescu A, et al. Patient Empowerment and Centredness. 2021 **4.** European Patients Forum. The Added Value of Patient Organisations. 2017. **5.** Wale JL, Chandler D, Collyar D, Hamerlijnck D, Saldana R, Pemberton-Whitely Z. Can We Afford to Exclude Patients Throughout Health Technology Assessment? Perspective. Frontiers in Medical Technology. 2022-January-25 2022;3doi:10.3389/fmedt.2021.796344

6. EU HTA Network. Strategy for EU Cooperation on Health Technology Assessment. 2014. http://ec.europa.eu/health/technology_assessment/docs/2014_strategy_eucooperation_hta_en.pdf