

Patient Engagement in EU funded projects

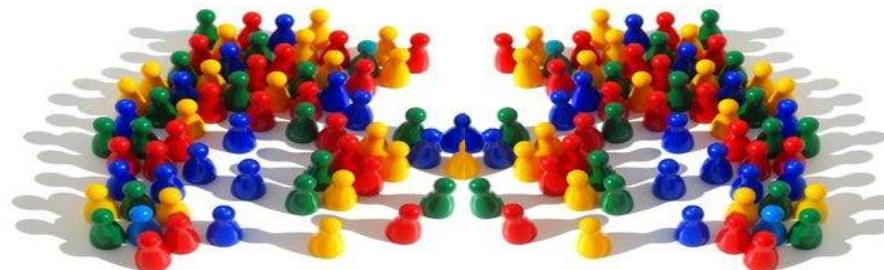
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“ A STRONG PATIENTS’ VOICE TO
DRIVE BETTER HEALTH IN EUROPE ”

Who We Are?

“EPF is the only European-level, non-disease specific umbrella patient organisation, and it provides a vital cross-disease perspective from a wide patient community into EU policymaking on issues that have a direct impact on patients’ lives in a national and regional context”.



Our Mission is:

To advance the interests of patients and patients' communities by strengthening their collective impact across Europe through effective advocacy, education, empowerment, and partnership.

Our Vision is:

A Europe where patient organisations are valued partners in creating equitable, person-centered, accessible, and sustainable healthcare systems, based on patients' unique expertise.

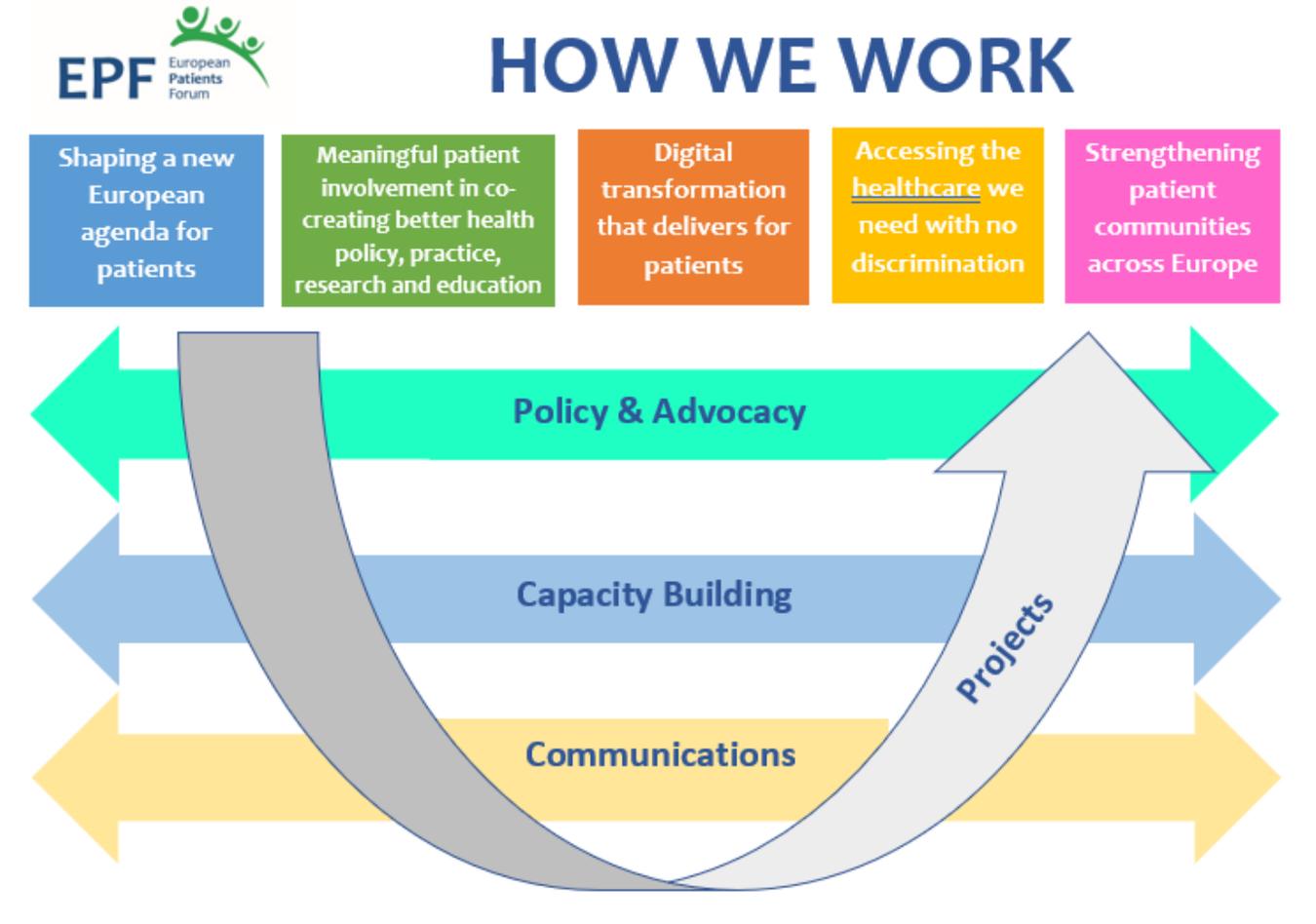
Membership

The backbone of our work



Driving Better Health for Patients in Europe

Focus on the **five strategic goals** of our Strategic Plan 2021-2026, which are complemented by **cross-cutting activities**.



Projects and initiatives

A diversified project portfolio aiming to incorporate the patient voice in health policy and practices



- We illustrate the patient perspective on behalf of larger patient communities;
- We look at aspects of the project that might undermine patients' values and needs;
- We “educate” partners to think and act in a patient-friendly manner .

OUR ADVOCACY WORK STARTS WITH YOU!

How we can get involved

- Project coordinator
- Work package or Task lead
- Consortium partner with no major responsibilities
- Advisor / advisory board member- don't forget to allocate funding to patients (travel and compensation for time investment)
- Each role comes with a different level of needed capacity, responsibility, rights, funding
- Count on our large network to connect to the right patients/patient organisations

- Invite us to get involved since the early stages of the proposal drafting;
- **No tokenism:** Meaningful involvement in the project (not just communications and dissemination, but everywhere we can have a say);
- Sustainable budget/No volunteer work.

Challenges

- Lack of human resources in pre-grant application phase;
- Reporting and admin requirements;
- Lack of capacity (lack of human resources compared to other partners involved in the project);
- Lack of expertise on technical matters;
- Lack of understanding of POs needs from other partners;
- High competition

The importance of building capacity and engagement

- Better alignment of research priorities with real unmet needs
- Improved design: ethics, practicalities, endpoints that are important
- Improved information material, informed consent
- Better recruitment, fewer drop-outs → less costly
- Researchers' assumptions are challenged → “a different reality”
- Wider dissemination of findings & championing of research
- Fostering public awareness of & trust in science



In conclusion...

From “patient-centred” healthcare



... to participatory healthcare



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