



## How to advocate to policy makers

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### Background on the European Patients' Forum

The European Patients' Forum (EPF, [www.eu-patient.eu](http://www.eu-patient.eu)) is the umbrella organisation of pan-European patient organisations active in the field of European public health and health advocacy. EPF was founded in 2003 to become the collective patients' voice at EU level, manifesting the solidarity, power and unity of the EU patients' movement.

EPF currently represents 59 patients groups – which are chronic disease specific patient organisations operating at EU level and national coalitions of patients organisations from many countries of the EU.

EPF's focus is patient advocacy, and project development and capacity building to support this - and we deal with cross-cutting issues affecting all patients, not disease or country specific issues. Our member organisations advance patient advocacy in their specific area

### Why advocate in health policy?

#### Will it make a real difference to patients, at the end of the day?

*"Yes it will, if we get it right, and we 'close the deal' to ensure whatever we achieve with policy makers to make legislation work for patients is translated into real world settings. The real stuff only starts when the legislation or policy is adopted."*

### Key issues to consider for Patient Organisations

Where and when to be proactive and agenda-setting in working with policy-makers, and where and when we need to be reactive, providing critique and changes to proposed legislation or policy development that will affect our groups.

Example of **pro-active** work – EPF manifesto '150 million reasons to act'  
[http://www.eu-patient.eu/Documents/Events/Manifesto/epf\\_manifesto.pdf](http://www.eu-patient.eu/Documents/Events/Manifesto/epf_manifesto.pdf)

Example of **reactive** work – EPF's input into the EU Directive on 'Patients' Rights on Cross Border Health Care'  
<http://www.eu-patient.eu/Initatives-Policy/Policy/Patients-Mobility/>

### Key issues on messaging and evidence for advocacy on health policy:

#### The passion and the proof

To advocate with policy makers Patient Organisations need **absolute clarity** what they want, why they want it, and why it is the **right way for policy makers** to go.

Patient Organisations need **consensus and unity** among their membership on the lines to take – without this a 'divide and rule' approach is an easy option for policy makers.

Patient Organisations need to decide on a case-by-case basis when to advocate for their own disease and when better to address the broader picture in alliances across diseases, e.g. in **collaboration with other patient organisations or umbrella networks**. Health policy decisions are often not made to address disease-specific needs!

Patient Organisations need a **robust ‘advocacy strategy’** on a policy issue together with a clear timeline with deadlines around external milestones – *example deadline for submitting amendments to legislative proposals in the European Parliament.*

On-going **intelligence-gathering** on the process and the issue is crucial. Patient Organisations need to be ready to modify they approach and tactics as the issue takes speed. They need to constantly do their homework.

Patient Organisations need to know **their audience – identify who is the key target** and research thoroughly – the lead policy maker or shaper – who are the ‘champions’ around that person?, who are their adversaries?. What information about this person will help to create a bridge towards our policy objective, what are his/her concerns, ‘pressure points’. What might mobilise her/ his support?

Patient Organisations need to decide on their **positioning and their style** – is it very moderate, solution-oriented, reasoned and reasonable, discreet or more direct, radical, uncompromising campaign/ media oriented?

*Example: ‘EPF high level round table on cross border healthcare – the deal breakers for patients’ on the eve of the Council Decision – all of the lead players were in the room, with EPF in the chair. [http://www.eu-patient.eu/Documents/Policy/Cross-borderHealthcare/EPF\\_position\\_summary\\_101125.pdf](http://www.eu-patient.eu/Documents/Policy/Cross-borderHealthcare/EPF_position_summary_101125.pdf)*

Different styles are appropriate for different issues, or even a combination when tackling a single issue, depending on your key audience.

How do Patient Organisations **work effectively with partners and allies** in driving home a policy issue to policy-makers?

*Example: EPF worked in collaboration with European Community Pharmacists on the Pharmacovigilance legislation to ensure an article on ‘direct patient reporting on adverse events’ <http://www.pgeu.eu/en/events/details/7-pharmacovigilance.html>*

Patient Organisations need readily **accessible messages/slogans and sound-bites**, e.g. ‘A strong and united patients’ voice’ ‘patients are part of the solution’, ‘150 million reasons to act’

And we need substantive **credible, scientific and anecdotal evidence** wherever possible.

*Example – EPF Position on the EU Reflection Process on Chronic Diseases <http://www.eu-patient.eu/Press/News-Archive/EPF-response-to-chronic-diseases-consultation-stresses-patients-central-role/>*

**Living with the outcome** of a legislative process: ‘The perfect can be the enemy of the good’.

*Example – EPF verdict on the ‘EU Cross-Border Healthcare Directive’ - **compromise** but important codification of rights that we can **build on**.*

And once Patient Organisations have been successful in changing a policy or a law – the work really starts. They need to make sure that **their members know and understand** what has been agreed, and can negotiate effectively in their contexts for effective implementation. Otherwise legislative change becomes meaningless.

*Example EPF strategy for ensuring ‘EU Cross-Border Healthcare Directive’ is properly implemented and monitored **from the perspective of patients** <http://www.eu-patient.eu/Documents/Policy/Cross-borderHealthcare/EPF%20Guidance%20on%20Cross-Border%20Healthcare.pdf>*

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