HOW TO INFLUENCE THE EU DECISION-MAKING PROCESS

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MALTA HEALTH NETWOR – THE PATIENT AND HEALTH POLICY

Outline

1. Patient organisations in the legislative process
2. Examples of Patient advocacy
3. A few tips!
“Hard Law”
Advocacy
The European Policy Cycle

Meet the European institutions

European Commission
European Parliament
Council of the European Union

"A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE"
The ordinary legislative procedure

European Commission
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European Parliament

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"A strong patients' voice to drive better health in Europe"
The ordinary legislative procedure

European Commission → European Parliament → Council of the European Union

"A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE"
Where do Patient Organisations fit in?

National coalitions vs. European umbrellas

"A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE"
Monitoring the work of the Commission (legislative proposals, opinions, Work Programme, Calls for proposals...)

Responding to public consultations

Raising awareness on what is missing

Proactive Advocacy Committees

751 MEPs

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Committees

- Send your positions
- Send amendments’ proposals
- Meet them to discuss!

- Awareness-raising: campaigning – WHAT is MISSING?

- Ask MEPs to ask questions to the Commission

Nationality

- Monitor what’s happening in the EPSCO Council: ‘emploi, politique sociale & consommateurs’

- Send position papers / Send amendments

- Whom to target?
  - National Ministries
  - Permanent representations in Brussels (Health attachés)

- Meet with the EU Presidencies (Trios)
- Organise events in the country of the Presidency

Political party

- Awareness-raising:
  - WHAT is MISSING?

- Ask MEPs to ask questions to the Commission

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A STRONG PATIENTS’ VOICE TO DRIVE BETTER HEALTH IN EUROPE
Once the text is adopted…

National coalitions vs. European Umbrellas

- Closer to European decision-makers (better access to European Commission, European Parliament’s Committees)
- In a better place to monitor the legislation at EU level
- Have a better “overview”, able to compare situations and transfer best practices whenever possible

- Closer to national decision-makers (including Council of the EU)
- Have a greater influence on MEPs from their country (they are voters!)
- Know about national-specific situations, realities
- Know about national legislation
- Closer to patients

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Example of patient Advocacy In the EU legislative cycle

Example: Clinical Trials legislation

What did we want?

1. Participation in ethics committee
2. Wide publication of CT Results
3. Consent

"A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE"
Example: Clinical Trials legislation

Impact Assessment
EC 1st Consultation + Meeting on the Revision of The Directive

2009

2010

EPF

2011

EPF STATEMENT

"A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE"

Example: Clinical Trials legislation

Publication of draft proposal

2012

Legislative Process

2013

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Example: Clinical Trials legislation

**Legislative Process**

- **2012**: Publication of draft proposal
- **2013**: Participation in ethics committee
- **2014**: Wide publication of CT results

**What did we obtain?**

1. Consent
2. Participation in ethics committee
3. Wide publication of CT results

"A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE"
"Soft Law" Advocacy

The EU & health

Article 168 TFEU: a limited competence in health:
- Responsibility for organisation of health systems and delivery of healthcare is with the Member States
- Principles of subsidiarity & proportionality
- Union action shall complement national policies

Binding legislation (regulations & directives) to harmonise Member States laws in some areas of exception, e.g. medicines, devices, cross-border healthcare:

"A strong patients' voice to drive better health in Europe"
Soft law

Soft law & collaboration for exchange of best practices

• **Instruments at EU level**: Recommendations, Opinions, Council Conclusions, exchange of best practices
• **Non-binding legally**
  • Still: demonstration effect can have a persuasive influence
  • Encouraging Member States;
  • An instrument when Member States can’t agree on the legal instrument to use?

EFA: Enabling air travel with medical oxygen

Problems

1. **Discriminatory practices**: some airlines charge for the use of medical oxygen

2. Each European airline have different Medical forms that require different approval periods.

3. Some cabin crews are inadequately trained on how to assist passengers requiring the use of oxygen.

Up to 7 times the price of the same round airfare trip for a normal passenger!
**EFA’s Strategy**

- **Publications**
  - Booklets,
  - Leaflets
  - Scientific abstracts

- **Meetings with key stakeholders**
  - International Civil Aviation Organization (ICAO)
  - European Aviation Safety Agency (EASA)
  - Airlines
  - European commission

- **Political actions**
  - MEP Keith Taylor
  - EP report

**EPF Patient Empowerment Campaign**

One-year patient-led campaign

- **Why?** To promote a common understanding and call for an EU strategy on Patient Empowerment
- **Who?** EU health Stakeholders & decision-makers
- **When?**
  - May 2015: major launch conference
  - November 2015: development of a Roadmap & Charter to advocate at the EP
  - June 2016: Exhibition at the European Parliament
a few tips

Become a database Ninja
Integrate Legislation timelines or input needed in your own organisation’s calendar.

Monitor the Commission’s website.

Subscribe to newsletters, RSS Feeds.

Your network, your informers!

THERE’s NO SUCH THING AS

Consult with your members

Your Legitimacy, your Credibility
Know Your Dossiers!

meeting is easy as a ☕
Find allies
And work together

Tailor your communications
trust your worth
	hank you for your attention!

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🐦 @hello_camille

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