

OVERVIEW OF KEY EU POLICIES AND LEGISLATION FOR PATIENTS AND ROLE OF PATIENT ORGANISATIONS

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28 October 2013

Zagreb, Croatia

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



Overview



1. Why EPF
2. EPF's role in EU health policy-making
3. Examples of our policy impact and priorities
4. Creating the right 'political' environment- the EPF Campaign
5. Closing the circle – involvement of our members at European and national level – united patients' voice

Why EPF was set up



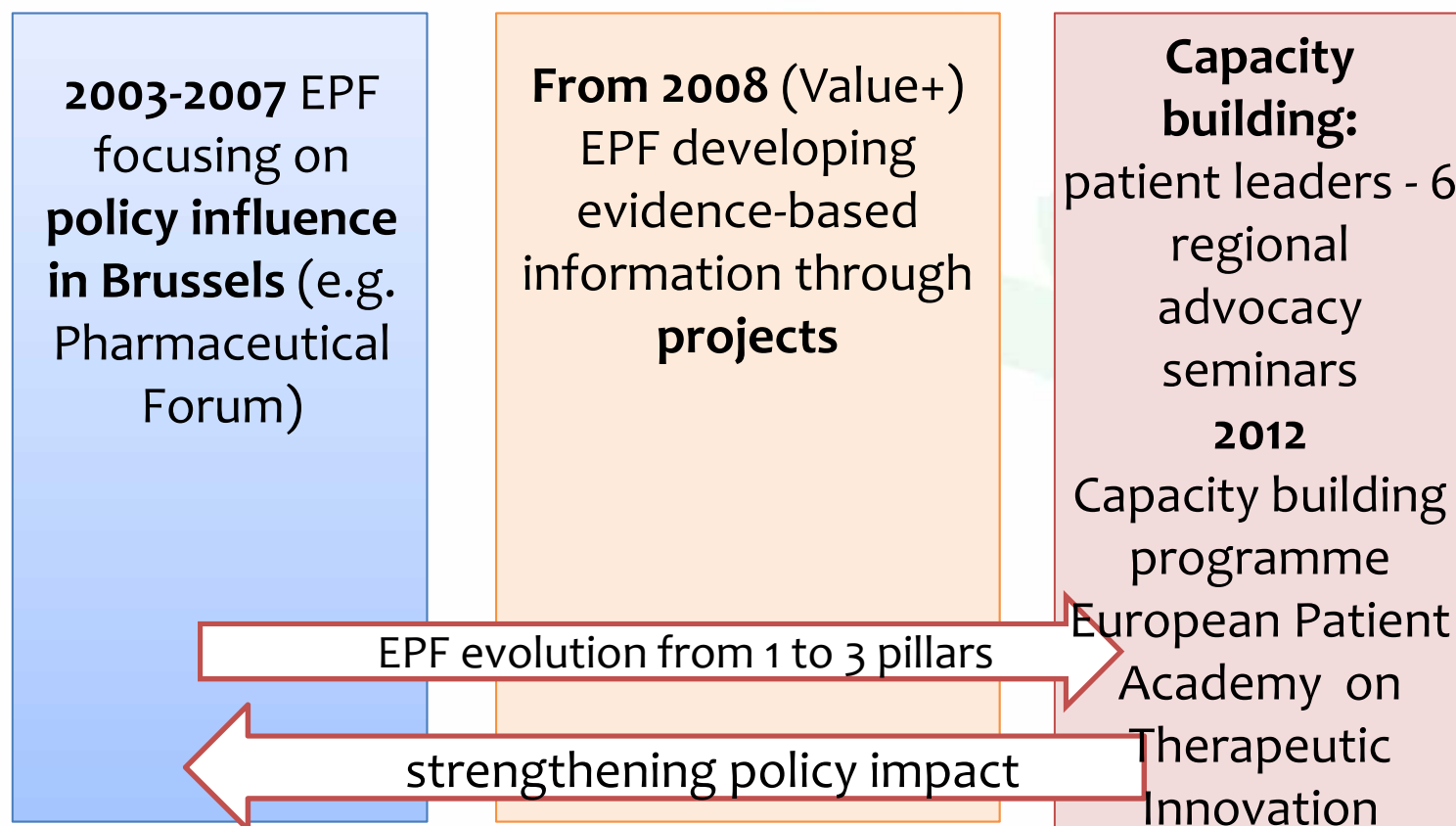
- Patients move from passive recipients.... to informed and engaged actors
- Patients = real partners in healthcare, together with health professionals and other stakeholders
- Growing expectations: quality, safety, and also sustainability
- Growing involvement: patient-centred care, self-management...
.... but patients are not consumers in the traditional sense
- The patient perspective is unique – experiential knowledge is an under-used resource for improving healthcare systems

Need for a united patients' voice on the wide range of issues affecting all patients to work effectively with EU Institutions

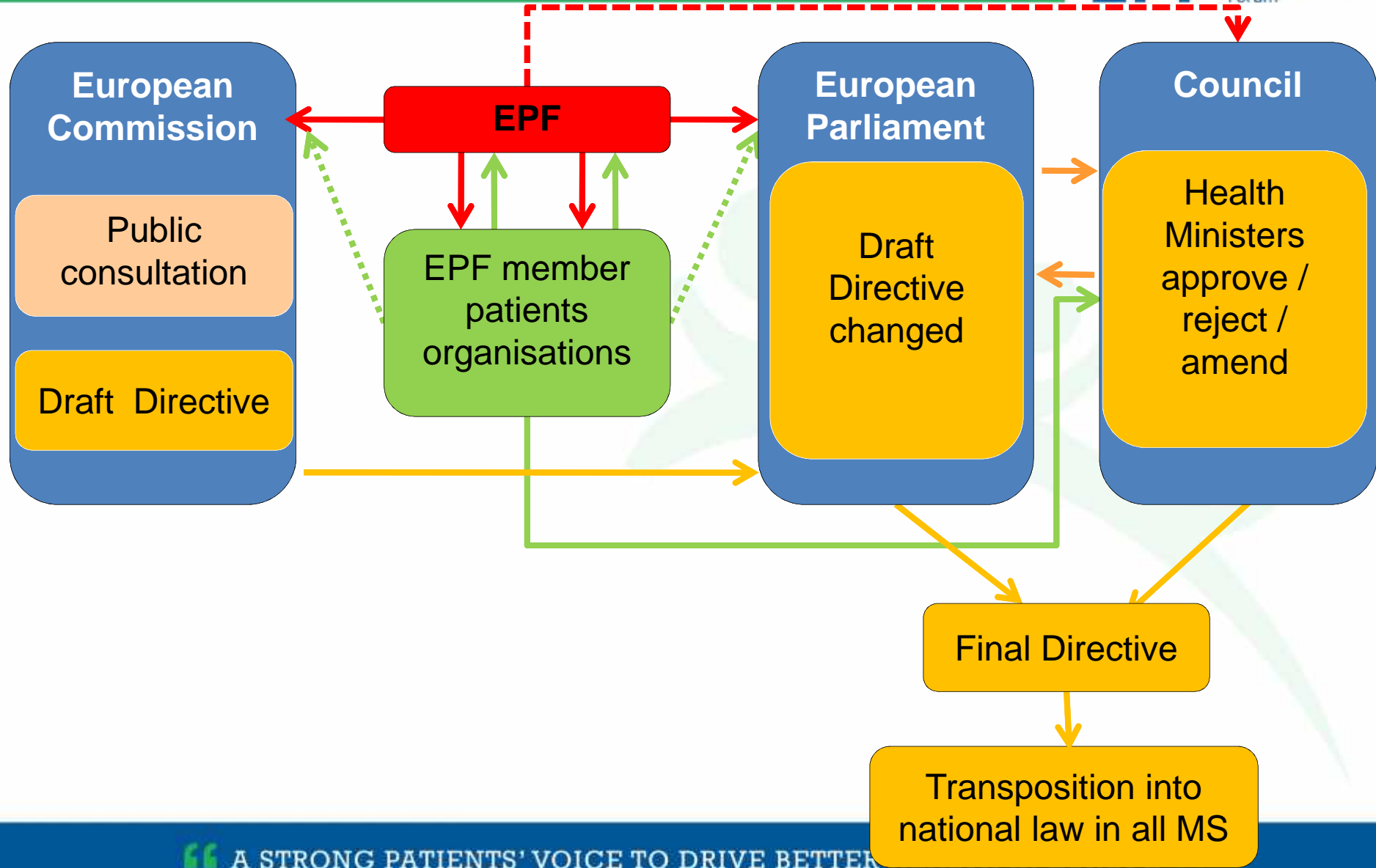
EPF: 2007-2013



Strengthening EU Patients' Voice



EU legislative process



EPF works with all EU Institutions



- **Commission:** participation in working groups; **pro-active** discussion on key patients' concerns, response to consultations, upcoming legislative proposals, etc.
 - Patient safety working group (DG SANCO), Access to medicines initiative (DG Enterprise), personalised medicine (DG Research)...
- **Parliament:** input into legislative process – working closely with Rapporteurs, involving **MEP champions** in supporting EPF's work
- **Council:** also through **successive EU Presidencies** on key priority areas
 - Belgium: Cross-border healthcare; Poland: Older Patients ;
Denmark: Empowerment: Lithuania : Sustainable HC Systems

Cross-Border Healthcare



- Draft Directive launched by EC in June 2008 , first reading by the European Parliament in April 2009
- Controversial dossier – much inter-institutional negotiation
- EPF High Level Round Table on the eve of the Council Decision – December 2010 under Belgian EU Presidency – *deal-breakers for the patients community*

Final outcome – EPF's Verdict : **A compromise rather than a panacea** ..some concerns on equity, lack of clarity etc

However.....

Cross-Border Healthcare



- EPF welcomes CBD – codification of **patients' rights** to access healthcare and be reimbursed
- Aspects of the Directive will help to achieve better quality care for *all* patients – cooperation on quality and safety, eHealth, HTA and rare diseases...
- Impact will only become clear in coming years– EPF will monitor and report on the experiences of patient organisations in this process.
- Crucially, we continue to work with EC and stakeholders on implementation AND very closely with our national members. Transposition deadline 25 Oct
- 4 Regional Conferences 2014– informal network of patient leaders - support and constructive critique

Pharmacovigilance Legislation



- Pharmacovigilance – preventing side effects of medicines and harm to patients
 - EPF advocated for *direct patient reporting* of adverse events
 - Just before EP vote, **Joint EP meeting** with European Community Pharmacists and the European Doctors' orgs
 - Highly **effective work with EP rapporteur-evidence based**
 - Draft Directive endorsed by European Parliament in September 2010 and adopted in early 2011
 - EPF working closely with our members regarding a **patient-centred transposition of the Directive**, and also with the European Medicines Agency – Member of Pharmacovigilance Regulation Advisory Committee (PRAC)

Key policy areas for EPF



Key EU legislation

- Clinical trials: Revision of EU Clinical Trials framework in progress
- Medical devices : revision of legislation in progress
- In vitro diagnostic medical devices: revision of legislation in progress
- Data Protection Legislation – striking the right balance – privacy, confidentiality and research
- Pharmacovigilance: Implementation phase, EPF cooperation with EMA re: information to patients on direct reporting, patient leaflets...
- Falsified medicines : implementation phase (EPF toolkit forthcoming)

EU programmes for the period 2014-2020

- Health programme (“**Health for Growth**”)
 - Health literacy, chronic diseases, patient empowerment
 - Research framework programme (**Horizon 2020**)
 - Biomedical and public health research, unmet patient needs, personalised medicine...
 - **Structural and Investment Funds - cohesion policy**
 - Health inequalities, investment in health at MS level, possibilities for PO to benefit...
 - EPF Toolkit
- EPF Strategic Plan 2014-2020**
- Defines our strategic goals and broad policy priorities
 - Ongoing work to contribute to above programmes – shaping annual work programmes, calls for proposals, feeding into policy

Key policy areas for EPF



“Soft-law” areas and non-legislative cooperation

- **Health Literacy / Information for Patients**
 - Cross-cutting priority, EPF & in cooperation with other stakeholders
- **Health Inequalities (COM) , Equity and Access**
 - Cross-cutting priority, focus on regional events & EPF campaign → EU platform
- **Patient safety & quality of care (COM, CR)**
 - EPF in JA PaSQ & EC working group
- **European Innovation Partnership on Active and Healthy Ageing**
 - WGs on Adherence, health literacy, **patient empowerment, integrated care** (frailty, nutrition)
- **EU chronic disease strategy, sustainable health systems**
 - EPF input into consultations & reflection process, EPF Campaign, EC tender on PE, CHRODIS-JA
- **eHealth and HTA, eHealth Stakeholder Group, EUnetHTA**

Partnership – EPF ‘s ‘leitmotif’



collaboration & partnerships

- EU Health Policy Forum
- EC working group on patient safety & quality of care
- EC initiative on corporate responsibility in the field of pharmaceuticals – ethics & transparency, access to medicines
- e-Health Users Stakeholders Group
- High-level group for health research (DG Research)
- EU-funded projects, joint actions, tenders – e.g. ChroDIS (chronic disease), tender on patient empowerment
- Etc

Platforms and partnerships with **all relevant stakeholders** – industry , public health NGOs, health professionals at EU level

Based on **ethics, transparency and respect for independence of policy positions**

EPF Election Campaign 2014



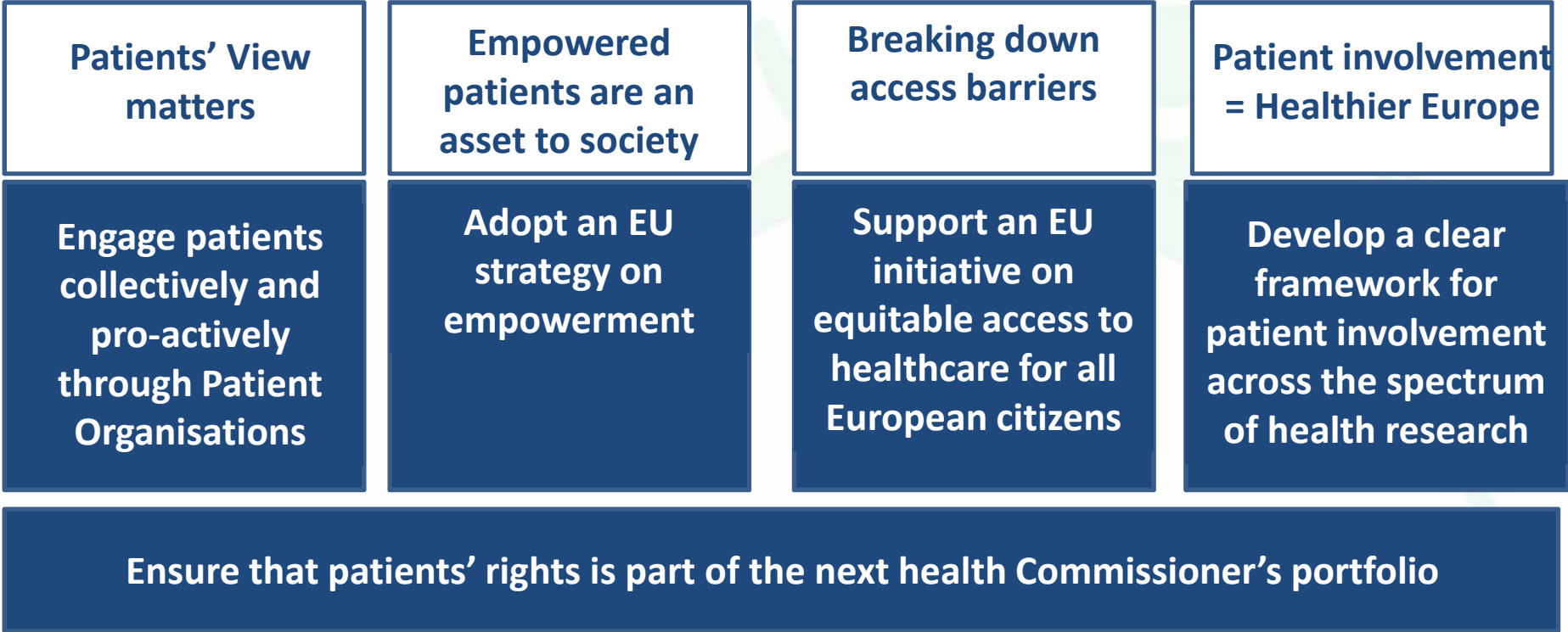
OBJECTIVE = create a sense of urgency & propose patients as part of the solution

- Raise the voice of European Patients
 - Patients' perspective = experts 'by experience'
 - Important role of national POs
- Raise awareness about EPF and our raison d'être
 - Our 'bridge" role
 - Key interlocutor on cross-cutting health issues
- Call for 'active' support of decision-makers
 - Newly elected , or re-elected MEPs from all MS , all groupings actively committed to a strong patients' perspective

Message House



Patients + Participation = Our Vote for a Healthier Europe



Manifesto

THE EUROPEAN PATIENTS' FORUM
MANIFESTO FOR THE 2014 EUROPEAN ELECTIONS

PATIENTS PARTICIPATION

OUR VOTE FOR A HEALTHIER EUROPE

PATIENTS' VIEWS MATTER

Our patients all share one common goal: to live as healthy, active and independent as possible. We have a unique perspective on healthcare. As consumers, we want quality care at a value that suits the way we live. As citizens, we have the responsibility to ensure that the health system works for all.

EMPOWER PATIENTS COLLECTIVELY AND PRO-actively THROUGH PATIENT ORGANISATIONS IN POLICY DECISION-MAKING TO ENSURE THAT ALL POLICIES AND PRACTICES REFLECT PATIENTS' REAL-LIFE NEEDS, PREFERENCES AND CAPABILITIES.

EMPOWERED PATIENTS ARE AN ASSET TO SOCIETY

We want to help partner the management of our countries according to our individual needs and abilities. We need to be empowered to do so. Empowered citizens with tailored high-quality information and health literacy, to enable us to make informed choices about our treatment and care. Empowered patients are good for healthcare. We take responsibility for our care in equal partnership with health professionals. We also take preventive measures, seek better diagnosis and effective treatment, which can reduce healthcare costs in the long run.

ADOPT AN EU STRATEGY ON PATIENT EMPOWERMENT, INCLUDING AN ACTION PLAN ON HEALTH LITERACY AND HIGH-QUALITY INFORMATION FOR PATIENTS ON ALL ASPECTS OF OUR CARE.

BREAKING DOWN ACCESS BARRIERS

Access to quality healthcare is a basic EU citizens' right. We will not accept a reality for some citizens that is different to the rest. Access means the availability of treatment, but also its affordability. Access also means non-discrimination. All patients in the EU deserve equitable access to care. Meeting diverse health inequalities is also good for health systems. If we do not get the care we need at the right time, we may develop more severe illness, reducing our capacity to be self-reliant and to manage health, and increasing costs. All EU citizens have a right to continue to live independently.

OFFER AN EU STRATEGY ON AFFORDABLE ACCESS TO HEALTHCARE FOR ALL EUROPEAN CITIZENS, THROUGH A MULTI-STAKEHOLDER PLATFORM.

PATIENT INVOLVEMENT IN HEALTHIER EUROPE

We, patients, or healthcare users, needs to be involved in designing more effective healthcare and to research to deliver new and better treatments. Meaningful patient involvement in research will lead to research that people we value. Patient-centred, targeted healthcare will lead to better quality of life for us and our loved ones and more cost-effective, equitable and sustainable health systems for us, other users, shareholders and Europe.

DEVELOP A CLEAR FRAMEWORK FOR PATIENT INVOLVEMENT ACROSS THE ENTIRE RANGE OF HEALTH RESEARCH, THROUGH THE CENTRE OF THE INNOVATION DIAMOND.

ENSURE THAT PATIENTS' RIGHTS IS PART OF THE 2017 HEALTH COMMISSIONER'S MANDATE.

I SUPPORT THIS MANIFESTO
www.epf.eu/manifesto



COMMENTS OF EUROPEAN CITIZENS
OUR VOTE FOR A HEALTHIER EUROPE

THE EUROPEAN PATIENTS' FORUM
22-25 MAY 2014
MILITARY PARK, BRUSSELS

OUR VOTE FOR A HEALTHIER EUROPE

FOR A HEALTHIER EUROPE WE NEED:
 - A STRONG VOICE FOR PATIENTS' NEEDS AND Wishes
 - A STRONG VOICE FOR PATIENTS' NEEDS AND Wishes

WHO WE ARE

WHAT WE ARE ALL ABOUT

THE EUROPEAN PATIENTS' FORUM

FOR A HEALTHIER EUROPE WE NEED:

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

Members' input is key



- Close consultation/ consensus with members on all major policy issues –Clinical Trials Regulation, Medical Devices Directive, Transparency Directive, Data Protection etc. throughout legislative process
... to arrive at credible, evidence-based, solution oriented positions that work for patients
- Mobilisation of their political allies and partners
- Once legislation is adopted, role of patient groups at national level **ABSOLUTELY CRITICAL**

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