Regional Advocacy Seminar Bucharest, 27 Oct 2011



europeanpatients'forum

A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE



- EPF why we exist
- Our policy priorities
- The Value + Model on Patient Involvement
- Projects patients' evidence base
- Genuine collaboration with Health Professionals with Health Literacy at the heart
- Moving forward together
 – future priorities , the next EU
 Programming period and why this matters



- VISION high quality, patient-centred equitable healthcare throughout the EU
- MISSION to present a strong and united patients' voice 150 MILLION PATIENTS
 - 51 members
- GOALS
 - Equal Access
 - Patient Involvement
 - Patients' perspective
 - Sustainable patient organisations
 - Patient Unity







- Building capacity
- Strengthening our policy impact
- Harnessing patients' own evidence
- Extending our membership
- Developing communications and partnerships



Key policy areas

- Patients Rights in Cross
 Border Health Care
 - Patient Safety
 - Quality of care
 - Health Literacy
 - eHealth
 - Clinical Trials
 - Medical Devices
 - Health Technology
 Assessment







- "VALUE +" on the meaningful involvement of patients in EU health projects and policy
 - 3 core deliverables widely distributed, translations
 - Landmark conference under the Swedish Presidency, Gothenburg December 2010
- EPF representation in major EU level health Forums, Consultative Committees and Working Groups **doubled** in the last year



VALUE + tools

Model of Patient Involvement

Toolkit for patients' organisations

Handbook for project coordinators,

leaders and promoters

- Policy Recommendations
- Literature review on patient involvement
- Database on EU health-related projects

Directory of patient organisations in EU

Overview of legislation on patients' rights





Their Impact





In a policy sphere

 Innovation Partnership on Active and and Healthy Ageing

In a programme environment

- DG RESEARCH
- IMI
- At individual research project level
 - RESPECT
- Capacity building level
 - Tools linked to Health Technology Assesment, Clinical Trials, Structural Funds, eHealth



EPF Project Pipeline 2011

Projects, launched, midway, to finalise

CHAIN of TRUST- confidence and trust in eHealth

eHEALTH GOVERNANCE - policy coherence and leadership

EUnetHTA - patient involvement in HTA

RENEWING HEALTH - Telehealth - Good practice/Roll out

RESPECT - Patient Involvement - Paediatric CTs

INTERQUALITY - Patient Involvement Health Systems



Project Pipeline 2012

Projects planned, to be launched

EUPATI – patient education on pharma research- IMI Call 3

SUSTAINS – patient centred electronic records

QUALITY OF CARE AND PATIENT SAFETY - Patient Involvement in patient safety

YOUTH PROJECT empowering young patients

NEW HTA PROJECT – FP7 in hospital setting

SyMChrom- FP7 chronic diseases and systems medicine



• Reinforcing national patient platforms' advocacy and campaign work using policy advances at EU level

Implementation of the Pharmacovigilance
 Legislation – Direct Patient Reporting

- Ensuring provisions of Directive on Patients Rights in Cross Border Healthcare are upheld

- Coordinated work on Health inequalities and information to patients, health literacy

• Stronger collaboration with Health Stakeholder Allies



- Strong relationship with Key EU Health Professional Groups
- ✓ European Federation of Nurses ' EFN'
- ✓ European Organisation of Doctors ' CPME'
- European Organisation of Community Pharmacists
 ' PGEU'
- ✓ European Health Managers Association ' EHMA'
- ✓ European Organisation of Specialist Doctors ' UEMS'
- ✓ European Society of Intensive Care Medicine
- ✓ European Federation of Dentists
- ✓ European Public Health Alliance



Starting point

- Commitment to health literacy, patient empowerment, and patient-centred disease management
- Commitment to dialogue , not monologue
- Patients as co-deciders of their health BUT quintessential role of Health Professionals TRUST, MUTUAL RESPECT, SYNERGY



- ✓ European Federation of Nurses ' EFN'
 - O Joint advocacy on the European Directive on Professional Qualifications
- ✓ European Organisation of Doctors ' CPME'
 - O Joint board meeting and 'Joint Principles'
 - O Advocacy on cross border healthcare
- ✓ European Organisation of Community Pharmacists ' PGEU'
 - Joint meeting in the European Parliament Direct Patient Reporting of Adverse events
- ✓ Recent initiative CPME, PGEU, EPF
 - Major Europeean Parliament event on Adherence and concordance



- Patient safety and quality of care
- EUNETPAS and the new Joint Action
- Acceptance, Confidence and Trust in eHealth Solutions
- CHAIN OF TRUST, eHealth Governance, SUSTAINS
- Reconciling quality and sustainability in health systems
- INTERQUALITY



2014-2020

Next EU Programming Period

Major focus – meaningful patient involvement and patient centred disease manageme

- New EU Public Health Programme
- Programme on Research and Development
 HORIZON 2020 health component
- Cohesion Policy and Structural Funds Health in All Policies

2011 – development of campaign strategy and partnerships



Key messages

- EPF is making a measurable difference
- Our strengths
- our members' expertise, experience and solidarity
- our uniquely patients' perspective
- our commitment to partnership
- Embedding Meaningful Patient Involvement in the EU health and social policy environment

