WORK PLAN 2014

Nicola Bedlington

AGM 2014

Brussels

A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE



Point of Departure

- New Strategic Plan 2014-2020
- New EU Programming Period 2014-2020
- European Parliament Election and new Commission in 2014 – finalisation of legislative dossiers, limited new ones
- Existing and new commitments to projects/ policy
- Importance of capacity building work
- Discussions with the Commission to take forward Cross Border Health Care Directive





NEW STRATEGIC PLAN



• Our **Vision** is

All patients with chronic and/or lifelong conditions in the EU have access to high quality, patient-centred equitable health and social care.

• Our **Mission** is

to ensure that the patient community drives policies and programmes that affect patients' lives to bring changes <u>empowering</u> them to be equal citizens in the EU.

New Strategic Plan

6 Strategic Goals

• Health Literacy 籇



- Sustainability and Quality of healthcare systems
- Meaningful Patient Involvement
- Patient Empowerment (rights and responsibilities)
- Sustainable Patient Organisations
- Non Discrimination

Focus on proactive, agenda setting advocacy

Clustering and "working group" approach, focus on priority areas to deliver on the strategic plan



Main Features

- Strong and vibrant campaign around the EP elections
- No Regional Advocacy Seminar but planning work for a major Regional event in Scandinavia in 2015
- Critical year of the European Patient Academy on Therapeutic Innovation – EUPATI -F2F training / content production
- Continued emphasis on young patients and older patients – initiation of critical work on other vulnerable and excluded groups







Focus



- AGM and fringe meetings development of working group approach
- More targeted survey work with our members capturing patient experience
- No single European conference but EPF partnering strategically with other players e.g. ENOPE
- 3 Regional Conferences on cross border healthcare opportunity to drive home core issues in a regional and national context based on our pilot in Brussels in

December



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- Extremely important phase of the capacity building programme –requires significant resources – tangible results in 2014 with core modules
- Fundamental commitment to monitoring and evaluating our work – accountability, learning, prioritising...



- Annexes to the draft work plan
- Tentative Calendar
- Overview of likely policy initiatives
- Overview of project commitments in 2014

FEEDBACK EPF WORKING GROUP ON ACCESS

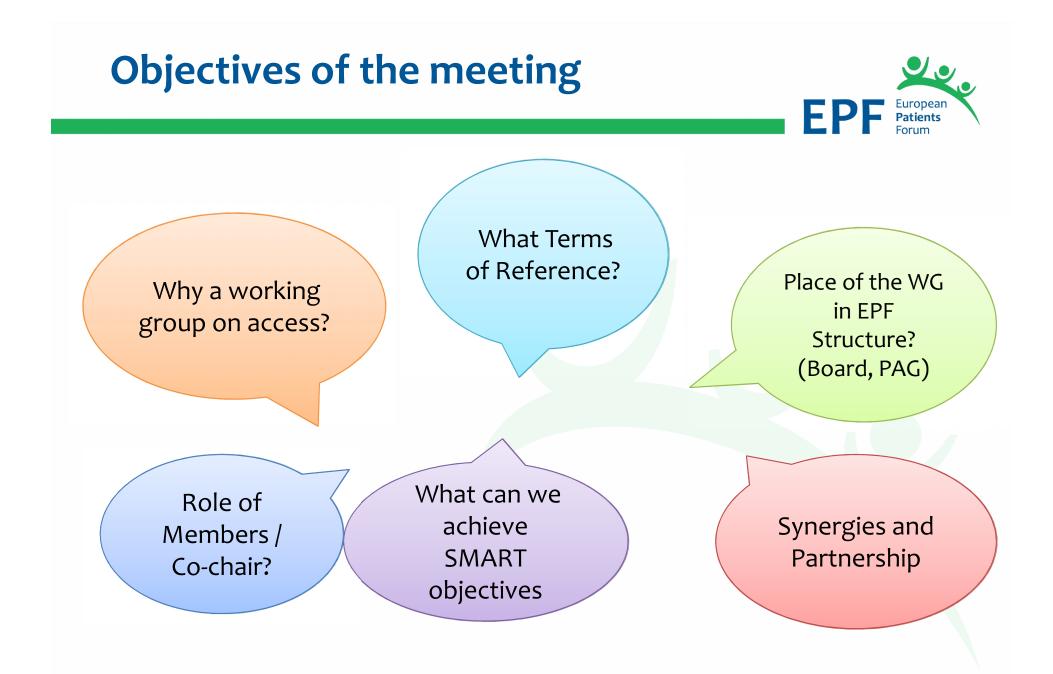
John Wubbe WFIP Rapporteur

13.05.2014

Brussels

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What the working group can achieve



- mapping exercise to ensure better coordination and exchange of knowledge between members
- The first task of the group is to come to a common concept of access what it means, access to what?
- Better data and indicators from the patients perspective are needed
- Evidence of the cost of non access
- Patient organisations' can show what happens behind the numbers





- We discussed the multistakeholder partnership on access: It should be patient focuses and patient led + collaborating on prevention
- Liaison persons with Board and Policy Advisory Group
- Need for a liaison with Patient Empowerment WG
- Governance: We discussed that it could be a steering committee instead of a chair

FEEDBACK EPF WORKING GROUP ON PATIENT EMPOWERMENT

Rapporteur: Tunde Koltai

12.05.2014

Brussels

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1. Priority themes

In the short term

- Definition
- Good and bad practices mapping
- Rights and responsibilities
- Relationship between patients and HCPs (Individuals and organisations)

In the medium and long term

- Equity and quality (reduce inequality and discrimination)
- Healthcare professionals mentality changed
- Patient empowerment is a part of prevention
- Patients involvement into the HCP curricula
- Recognition of rights and responsibilities of patients

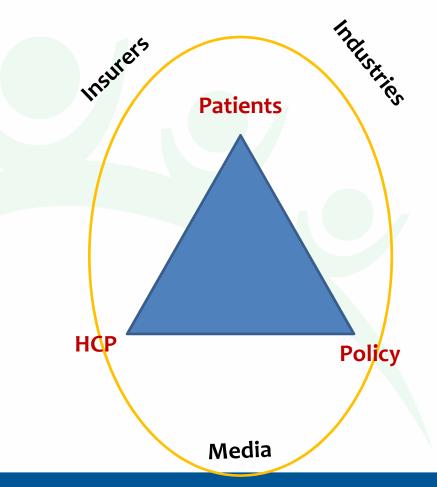
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2. Target audiences (outside EPF)



- Patients (individuals and patients organizations)
- Policy makers (European, national and local level)
- Healthcare professionals (individuals and organizations)
- Insurance organizations
- Industry

 (pharmaceuticals, medical devices, IT etc.)
- Media



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3. Outcomes and outputs

In the short term

- Definition of patient empowerment
- Toolkit

In the medium-long term

- Awareness campaign
- Monitoring / indicators
- "Enforcement mechanism"
- Partnership/networking (with HCPs, policy makers)
- Concept of training for patient organisations
- Training "peer experts"

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BACK UP SLIDES

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Illustration : Patient empowerment and the EU response to chronic disease



Patient empowerment as a major thematic work area – focus of one of our 2 pilot thematic working groups including:

- Policy recommendations for patients' involvement in healthcare, including patient-focused use of innovative technologies and services.
- Common understanding of patients' rights and "patients' responsibilities"
- health professionals' competences to support empowerment
- patient friendly health care systems
- Partnering in the 2nd ENOPE conference, "Power of patients 3.0"
- Contribution to JA CHRODIS
- Participation in an EC tender on self-management

Illustration Health inequalities from the patients' perspective



- Second working group
- Focus on equity of access, building on events of 2012 -13 and EPF's EU elections campaign messages
- Comprehensive Survey of EPF membership in 2013-2014 on their perspective of patient access, including impact of austerity measures in different countries
- Follow-up on progress report on the EC communication "solidarity in health"
- Follow-up on EU Transparency Directive and CBHC
- Leadership in the 'Access' Partnership
- Exploration of the scope of the structural funds for our member organisation and on-going communications

Illustration : Non-discrimination and inclusiveness



- In 2013 EPF members selected non-discrimination as a critical issue for patients and a core strategic goal for EPF
- position paper to be developed in 2014, in context of EU legislation on equal treatment discrimination on the grounds of health status
- developing collaboration with the EU fundamental rights agency and fellow NGOs- exploring vulnerable or marginalised patient groups' access to healthcare
- continued follow-up of the needs and rights of older patients (position paper on older patients finalised in 2013) as well as young patients (EPF youth strategy)

CAPACITY BUILDING PROGRAMME

EPF AGGM 12,13 May

Brussels

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RATIONALE & OBJECTIVE



- Appeal from our members
- Tradition of great capacity-building activities
- Need for a more tailored approach
- Thinking about sustainability

Strengthening the capacity of both Member State and European Patient Organisations to enable them to be more effective in achieving their mission and objectives and being part of EPF





- Capacity needs' assessment exercise true comprehensive learning exercise
- Strategic plan = a clear framework to operate
- Shift in thinking: working according to a plan and not to a situation
- Patient organisations seen as more professionals
- Better relation with sponsors additional funding
- Cohesion and team building

Whole process a capacity-building activity in itself!

ACTIVITIES 2014



Hungary, Romania:

• Training delivery: governance, fundraising, communication

Bulgaria, Poland, Slovakia:

- Strategic Planning process completed
- Strategic plans for 26 orgs
- Training on Operational Planning
- Development of annual plan 2015 for 26 orgs

European Patient Organisations:

- Strategic Planning process completed
- Strategic plans for 4 orgs
- Training on fundraising

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