

EPF INDUSTRY ROUNDTABLE

05/09/17

Brussels

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

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WELCOME

Marco Greco – EPF President

05/09/17

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LOOKING AHEAD - EPF STRATEGY AND FRAMEWORK PROGRAMME TO 2021 – CONTINUE, CONSOLIDATE, GROW

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How Has our Environment Changed?

- Situational analysis conducted by an external consultant (March – July 2017);
- Structured around 5 main areas:
 - Politics
 - Economy
 - Technology
 - Society
 - Recommendations for action
- Report to be made public.



Recommendations for Action

1. EPF should drive the agenda and be active, also in the wider policy debates that may influence health
 - Digital health;
 - Understanding the value of health;
 - Europe's future and the importance of health in EU collaboration.
2. Europe = Brussels + Member States
 - Work beyond the Brussels village;
 - Work more at MS level through national coalitions;
 - Leverage and export national good practices.



EPF Strategic Plan Mid Term Review

- EPF Leadership meeting - April 2017;
- Governance proposals for changes:
 - Vision, Mission;
 - Inclusion of definitions;
 - The wider Europe;
 - Membership categories.
- Access - minor changes;
- Empowerment, building sustainable POs - remain same.

- **Old**

*“All patients with chronic and /or life-long conditions in the **EU** have access to high quality, patient – centred equitable health and **social care**”.*

- **New Proposal**

*“All patients with chronic conditions in **Europe** have equal access to high quality, patient –centred health and **related care**”.*

- **Original**

Our mission is to ensure that the patient community drives policies and programmes that affect patients' lives to bring changes empowering them to be equal citizens in the EU.

- **New Idea – More Focus**

Our mission is to be the collective, influential patient voice in European health and related policies and a driving force to advance patient empowerment and patient access in Europe.



Values to Remain the Same

- Explicit section in strategic plan with a definition of access (5 A's), piece on PACT;
- Definition of empowerment – from EMPATHIE research.

Upcoming Constitutional Reform 2019

- Wider Europe – impact assessment 2017;
- Youth Board member;
- EUPATI alumni become a consultative group;
- Enhance links with on-line communities;
- Encourage strengthening of national coalitions;
- Stress complementarity between membership categories.



Framework Programme Agreement



2018-2021 – Operating Grant from the Commission – EPF’s Operational Activities (*not including projects and our capacity building programme*).

OBJECTIVES

1. Meaningful, structured and systematic patient involvement;
2. Sustainable health systems for all;
3. Impactful Patient Organisations.

MAIN PILLARS OF OUR WORK

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Meaningful Patient Involvement

- Build on our ‘assets’ to date
 - Value +;
 - EPF Charter and Roadmap on Patient Empowerment;
 - PROSTEP, PISCE , EMPATHIE.
- Develop a patient-led framework on good practice on patient involvement
 - Recommendations – PI as a ‘sine qua non’, added value;
 - Support adoption of good practices: co-design and evaluation of healthcare, health research, patient-driven technology solutions.

Not Patient Engagement In Medicines R&D – IMI project

- Accessible, Equitable Healthcare
 - UHC campaign follow-up – roadmap to SDG 2030;
 - PACT;
 - Value and pricing;
 - Prevention from our perspective (nutrition, vaccines).
- HTA
 - EUnetHTA , EU HTA collaboration post-2020;
 - Active member HTAi Patient and citizens' subgroup.
- Social Inclusion and Non-Discrimination
 - Supportive working spaces- reasonable accommodation;
 - Close collaboration with organisation representing vulnerable groups
 - roadmap, Fundamental Rights Agency.

Sustainable Health Systems for all

High Quality, Patient-centred Healthcare

- Patients' perspective on health systems' performance (PRIMS, PROMS - OECD);
- Health system strengthening – WHO;
- Digital health agenda – dedicated working group;
- Health literacy – including digital, scientific literacy.



Sustainable Health Systems for All

Effective Implementation of EU Legislation

- Patients' rights in cross-border healthcare;
- Clinical Trials Regulation and Patients' data;
- Pharmaceutical legislation – EMA;
- Medical Devices and IVD – secondary legislation.



Impactful Patient Organisations

Strengthening the Capacity of the Patient Community

- EPF Leadership Meeting;
- Patients Advocates' Seminar (PAS);
- EPF on the spot;
- EPF resource centre;
- EPF breakfast briefings and webinars.

In parallel, continued investment in EPF capacity-building programme

Impactful Patient Organisations

Preparing the Next Generation of Patient Advocates

- EPF Youth Group
 - Non-discrimination, sexual health, mental health;
 - Summer Leadership Training Programme;
 - European Solidarity Corps;
 - European Health Parliament.



Legitimacy and Representativeness

- New membership drive;
- Reflections on the wider Europe;
- Supporting emerging national coalitions;
- Transparency and ethics guidelines;
- Informal networks and new stakeholders.



Impactful Patient Organisations

An Empowered and Engaged Patient Community

- Support cross-fertilization (cluster approach);
- Spark engagement and drive higher levels of participation (members' expertise database, members' participation monitoring tool).

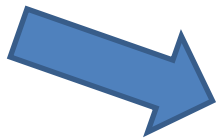


EUPATI = EDUCATION

- *as a permanent EPF programme long-term-major focus on sustainability and a viable 'business model' beyond 2019.*

PARADIGM = ENGAGEMENT

- *A framework and tools for structured patient engagement throughout the life cycle of medicines.*



How do we integrate these in the medium term and optimise cohesion – creating a single 'hub' ?

- Patient Focussed Medicines Development (PFMD) – Founder and member of the advisory board;
- Continuing cooperation with other international bodies driving patient engagement PARADIGM (HTAi, PCORI, DIA);
- ISPOR – supporting ISPOR’s drive to embed patient engagement in its body politic;
- Closer cooperation with WHO, OECD;
- Ever-closer relationship with IAPO on wider Europe.

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MAKING THE DIFFERENCE FOR EUROPE'S PATIENTS (2016-2018)

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“What
Access
means to
us”

2015 - EPF Definition of Access: “the 5 As”



“The
situation
we face”

2016 - EPF Report on Access



2017 - EPF Campaign on Universal Health Coverage

“Our
claims: we
need to
take
action”



Universal Health Coverage
For All.
#Access2030

“What needs
to be done to
make equity of
access a reality
for all”

2018 - EPF Roadmap towards achieving Universal Health Coverage for all by 2030 dissemination and implementation

2016 Survey on Access – What Did We Learn?



Safety and **quality of healthcare** in the EU is unequal



Lack of appropriate resources being **efficiently invested** in healthcare



many patients face **financial hardship** as a result of illness



Organisational changes needed to ensure the package of services covered healthcare system is tailored to the needs of patients



Majority of patients and carers **experience stigma** when seeking or receiving healthcare



Calls on decision makers to commit to a long-term vision where **equity of access and universal health coverage are a reality** for all patients in the EU

- **Raising awareness** about the **gaps** and **barriers** patients face in accessing healthcare;
- Fostering **more EU cooperation** and **political commitment**;
- **Access Roadmap: key political actions** towards achieving UHC for all patients in the EU by 2030



What Happens after the Campaign?

- **Equity of access** will continue to be a high priority:
 - **Support the 2030 Agenda** focusing on SDG3 on health, building on the outcomes of 2017 campaign – primarily the Roadmap
 - **Linkages to other EPF work**, e.g. on non-discrimination, quality of care, access to medicines...
- **Increase collaborative work with the health community and institutions**, reinforcing the role of health and its cross-sectoral importance, also **in the framework of the SDGs**

Patient Access Partnership - PACT



- **2016: two events** of the **MEP Interest Group** on Patient Access to Healthcare and major **regional conference** in Sofia;
- **2017: Lithuania country roundtable** to encourage multi-stakeholder collaboration on the implementation of the European Semester Country Specific Recommendations; **two events** of the **MEP IG**;
- **2018: Major PACT conference** following up the Vilnius Declaration and Riga Roadmap, particular **focus on HTA** and further **country-level roundtables** in the CEE countries.



Cross-Border Healthcare

- Roundtable on 4 December 2017 in Brussels → work with EPF's network of patient representatives in 2018 to monitor implementation and publish a patients' report in 2019.

Quality and Safety of Care

- 2017 recommendations for core competences for patients and families, Position Paper on quality based on 2016 patient survey;
- 2018 and beyond: the patient perspective on quality and patient-relevant outcomes – engagement with OECD activities PARiS initiative;
- 2018: EPF consensus statement on patient's rights;
- 2018 policy brief with a patient perspective on low-value care/waste (OECD) → awareness of patient community.

Access to Medicines

- Work with DG GROW, Medicines For Europe, EMA – information for patients on **biosimilars** and generics;
- Continued engagement in debates on **access** to medicines based on EPF's (updated) position paper.

Non-Discrimination

- **Youth Group:** advocacy on equal treatment – healthcare, education, workplace;
- Ongoing involvement in the **Fundamental Rights Platform**.

Medical Devices

- Work with the EFGCP EUDAMED Task Force, Patient-MedTech Dialogue, **communicating new EU legislation** to patient communities.

PATIENT EMPOWERMENT



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Empowerment Key Milestones

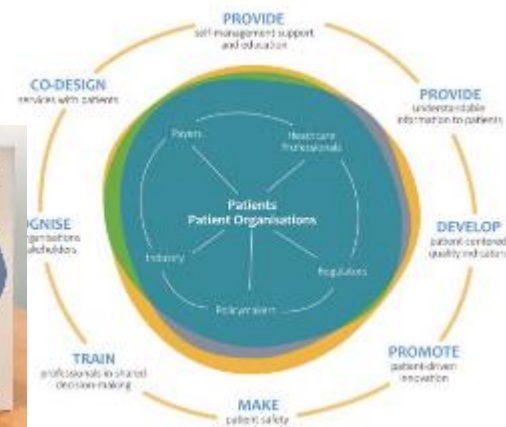
“Patient empowerment = a policy priority”

2014 - EPF leads WP in EMPATHIE Tender Study
Strategic Plan 2014-2020 includes PE as a priority area



2015-16 - EPF Campaign on Patient Empowerment

2016 - The Patient's Charter and Roadmap



2018 → Meaningful, Systematic & Structured Patient Involvement

Building on the Patient Empowerment Campaign

- Continued advocacy and engagement based on the Patient Empowerment Charter & Roadmap – 2017 PE Toolkit for patient organisations;
- Dissemination and engagement with wide range of health stakeholders;
- Follow-up on the Roadmap, incl. implementation of **Patient Safety action**;
- **Health literacy** remains important priority – incl. digital literacy, patient safety, public health, nutrition...;
- **Digital health**: focus on patient-centred solutions, ethical sharing of and use/re-use of patients' data;
- 2017 briefing on Big Data, Patient Survey on data sharing and electronic health records.

Meaningful, Systematic and Structured Patient Involvement

- From concept of empowerment to putting it into action, tying various strands coherently together;
- 2018 and beyond – four-year plan to 2021;
- Awareness of concept “meaningful patient involvement” incl. updating and extension of the “Value+” model;
- Criteria of ‘good practice’ as defined by patients;
- Mapping & sharing good practices and innovative examples;
- Highly complementary to PI initiatives in medicines r&d – PARADIGM, EUPATI...

Patient involvement potential in healthcare is under-recognised and lacking overall “know-how”



CAPACITY BUILDING & EPF MEMBERSHIP

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Membership - A Vibrant Network

- **74 members:** EPF has been growing consistently in the past years and gained 7 new members in 2017 (3 new countries and 3 new disease area);
- **AGM and Leadership Meeting:** highest participation rate ever (75 people from 26 countries);
- **National Coalitions Meeting (October 2017):** a new format to enhance strategic cooperation among National Coalitions on regional and European level;
- **EPF Youth Group:** increasing visibility
 - Participation in +2 international fora as speaker;
 - + 20% of likes on the Youth Group Facebook page and followers on Twitter.



- **Enhanced cooperation with our NGO partners** (EPHA, ECL, BEUC, HAI Europe, PICUM...) and joint actions (#EU4HEALTH);
- **Structured dialogues with trade associations:** MedTech Europe, EFPIA, Medicines for Europe, cooperation with COCIR;
- **Upcoming collaboration meeting – 5th December**



Membership: Plans for 2018

- **Reinforcing the role of the patient community on the health scene:** Leadership meeting, follow-up activities after the publication of the report on the added value of patient organisations;
- **Strengthening the capacity of the patient community:** Patient Advocacy Seminar;
- **Reinforcing patient organisations' legitimacy and EPF representativeness:** dissemination of the transparency guidelines and mapping of raising stakeholders;
- **An empowered & engaged community:** creation of monitoring and engagement tools.

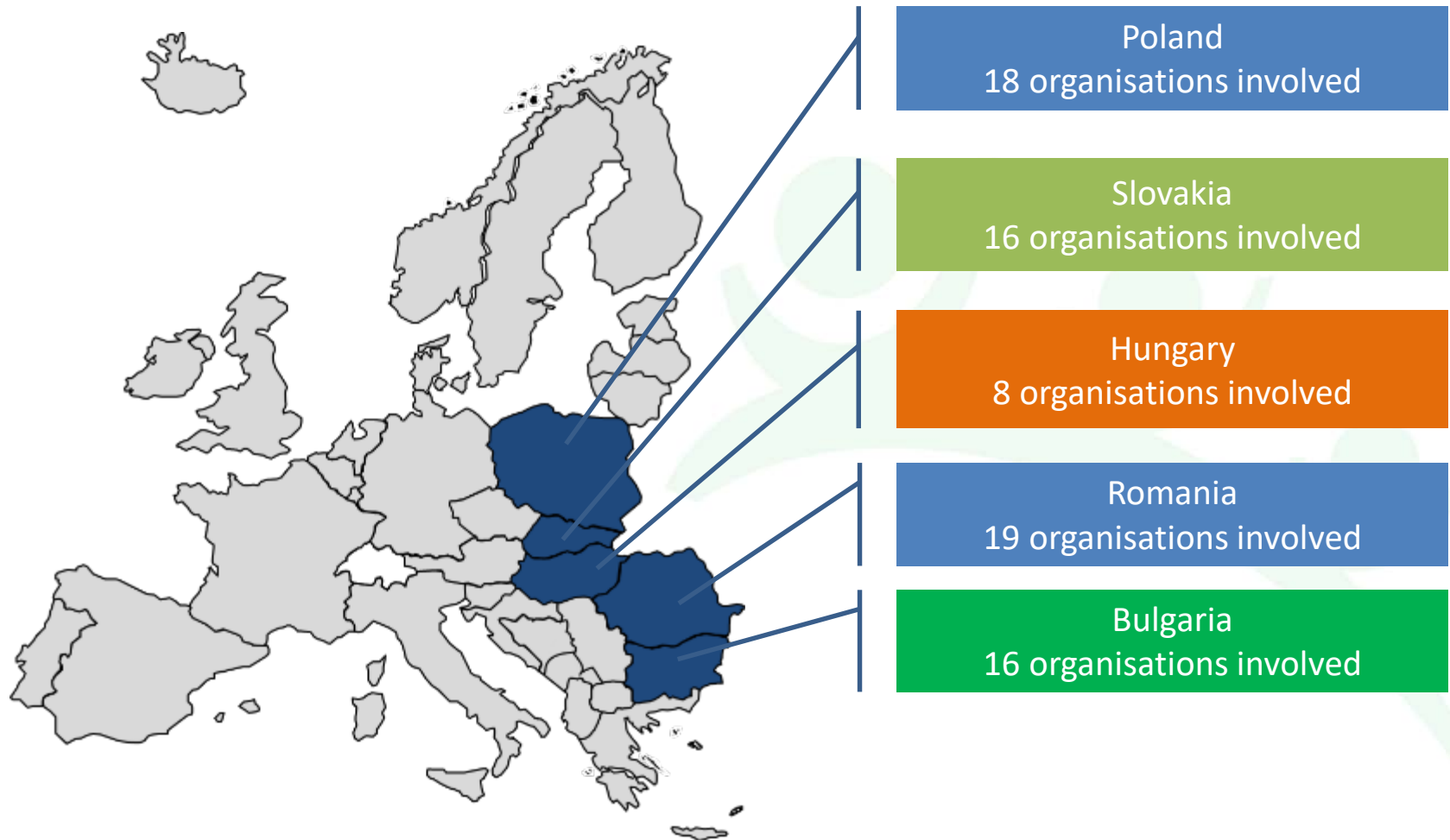
Developing a common vision

Enhancing our skills

Continue to improving ourselves

Further exchange

EPF Capacity-Building Programme



CB Programme-2017 Highlights

Bulgaria

- Training module on Fundraising - completed in summer 2017.
- EPF translated its Fundraising toolkit into Bulgarian
- “The organisations feel stronger and more equipped after the training, they increased their self esteem”;

Hungary

- Module on **Strategic Communications** in progress.
- New situational analysis on the healthcare sector in Hungary;

Romania

- Current module: Strategic Communications
- Organisations are developing, most of them for the first time, their communication strategy;

Slovakia

- Experimenting! For the first time we successfully paired more experience organisations and less experienced ones;

Poland

- 1st module! Focus: the added value of patient organisations
- Objectives: reinforcing the Polish patient community & fostering cooperation among different organisations;

KEY FINDINGS IN THE REGIONAL CONTEXT:

- Overall, **healthcare financing is poorly organised**, vulnerable to external financial risks, and unsustainable;
- **Improvements in the quality of Balkan healthcare service delivery systems move slowly**;
- Corruption is widespread in most of the region;
- The **Laws on the Protection of Patients' Rights are not fully implemented**;
- **POs acknowledge the need for organisational capacity building support**, although it seems there is a greater interest in **technical and thematic issues**;
- Overall, **patients' sphere of influence is weak**;
- **Patients involved in this research very much appreciate the possibility of having regional cooperation among patients' groups across the Western Balkan countries.**

Leadership programme – Vienna, 2-5 July 2017

Vision

“To create a platform where young patients’ advocates would empower, inspire and learn from each other.”

- This year’s theme: Overcoming Discrimination;
- Key objectives:
 - Build/strengthen patient advocacy and leadership skills
 - Empower young patients
 - Boost young patients movements across Europe
- 40 participants, 3 full day sessions;
- Young patients, patients advocates and representatives;
- Age range: 18-30.



Capacity Building Plans (2017-2018)



- EPF will continue to offer thematic training modules in Bulgaria, Slovakia, Hungary, Romania and Poland;
 - **Slovakia:** EPF will launch the first module fully dedicated to Advocacy (2nd half 2017)
 - **Bulgaria:** EPF will continue working on Fundraising focusing on coaching and peer to peer learning;
 - **Western Balkans:** explore potential actions



- EPF will work on a centralised monitoring tool for the whole CB programme;
- **Summer Training for Young Patients' Advocates** for young patient leaders (summer 2018).



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COFFEE BREAK



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EU HOT TOPICS Debate

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THE ADDED VALUE OF PATIENT ORGANISATIONS

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Why a Report on the Added Value of POs?

- **Say who we are** - to dispel the confusion that sometimes exist around patient organisations and differentiate them from other stakeholders;
- **Building the trust** - to position patient organisations as legitimate stakeholders and reliable partners;
- **“Our contribution is wider than that”** - to raise awareness and highlight the added value they have in different areas (beyond medicines development);
- **Responding to criticisms** - to respond to the regular hostile comments towards civil society organisations, without being complacent.



About the Report

Methodology



Written by two external consultants

Data emanates from a survey conducted by EPF between September 2016 and February 2017 (35 respondents);

8 interviews: patient organisations, Civil Society Europe, MEPs, IMI, EMA, Robert Madelin, Industry partners...;

Desk Research

Letter to Juncker (and #EU4HEALTH)

Transparency Guidelines

Target Audience

- EU & national decision-makers (MEPs, DG SANTE, Council);
- Health professionals;
- Payers;
- Industry;
- Patient organisations at different levels (for their own advocacy).



Structure of the Report

Main Roles of Patient Organisations

Policy and Advocacy

Capacity-Building & Education

Peer Support

Research, Technology and Innovation

Key Findings

Policy & Advocacy

- They provide the “**end-user perspective**”- POs help policy-makers understand the experience of living with a disease or condition;
- **Active at all stages of policy development** and in a range of institutional settings;
- Work across a range of policies;
- Contribute to a more **nuanced and balanced policy-making**.



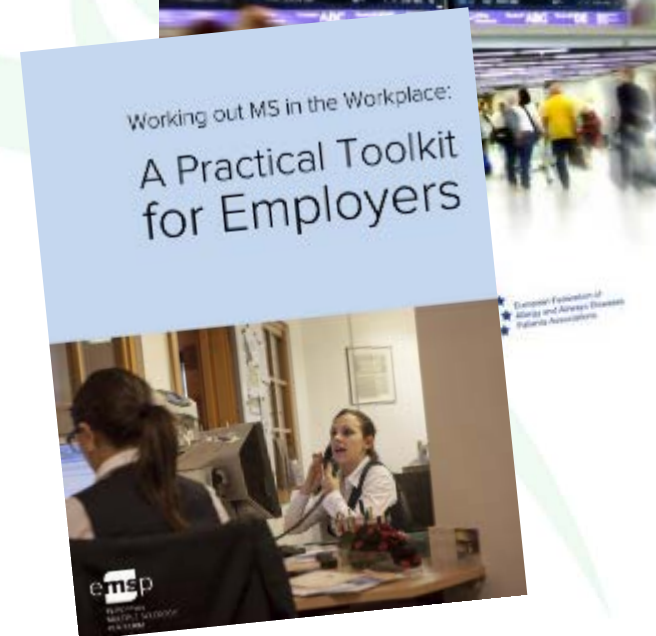
80% of respondents are active in advocacy activities at European level

Top 4 advocacy activities reported:

- Monitoring policies and informing members (72%);
- Responding to consultations (72%);
- Meeting with decision-makers (76%);
- Participating in advisory bodies (EU or national) (76%).

Capacity-Building & Education – POs as Capacity-Developers

- POs work towards strengthening the **organisational management** and governance of their constituencies;
- **Capacity-building targeted at:** their members, but also industry, policy-makers, academia and the media (through dissemination of info, educational initiatives, conferences...);
- POs play a key role in promoting and advancing **health literacy** – making sure information provided to patients is both of a high quality and accessible - (Especially true in the era of digital health information).



Key findings

Peer Support

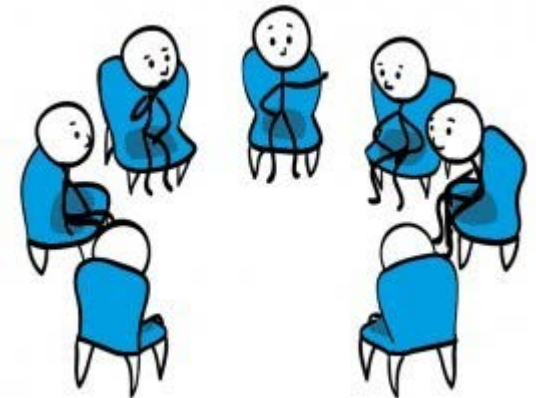
- Support targeted at individual patients.

Consists mainly of:

- Peer mentoring;
- Counselling or listening services;
- Legal and financial support.

(Mostly by national coalitions or local patient organisations, but not only).

37% of respondents offer support of some sort to individual patients



Research Technology and Innovation

- Data collection, reports, studies...



Europe-wide
survey on the
social impact
of rare
diseases



Benchmarking
exercise on
national
dementia
policies

- Co-design, development, application and monitoring of disruptive innovations for healthcare;
- Pharma research and development: from tokenism to involvement from the early stages and priority-setting;
- Increasing the capacity and capability of patients to understand and contribute to medicine research and development (ex: EUPATI).

- Lack of resources & funding, lack of unrestricted funding;
- **Objectivity** (??);
- **Credibility & alleged lack of independence;**
- **Professionalisation vs. representativeness;**
- Overcoming the culture of tokenism;
- **Lack of performance measurement** – or rather lack of knowledge on how to measure the impact of patient organisations?

Some reflections and key messages

- “The approach to **scrutiny** placed on patient organisations to provide evidence of their added value and impact is **not routinely** applied to other health stakeholders such as the pharmaceutical industry, health insurers or health professionals’ associations.”
- “**Healthcare systems in Europe needs to be built in cooperation with patients as end-users**, and on the principle of shared responsibility for preventing diseases at community and society level: the value of patient involvement in policy and research should be clear to all, and such involvement should become an objective in itself”.



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CONCLUSIONS & NEXT STEPS

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