

THE EUROPEAN PATIENTS' FORUM

Adherence and Concordance

EPF Position

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EPF President

24 November 2016

1st Acto Symposium, Namur

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

About the European Patients' Forum



- European Patients' Forum
 - Umbrella organisation founded in 2003
 - Independent & non-governmental
- Our members
 - 67 patient groups
 - Disease-specific EU & national coalitions
- Our vision
 - All patients in the EU have **equitable access to high-quality, patient-centred** health and social care
- Our mission
 - Ensure the patient community drives positive change → patients as equal citizens



European Commission – 80% of operating budget + co-funding of projects (HP, Horizon2020, CIP, IMI-JU...)

Unrestricted grants – commercial sector: 19% of operating budget + project portfolio co-funding

Membership fees: 1% – annual fee €100-1,000 depending on organisation's resources

Commitment to transparency and independence in all aspects of our work

[Code of Ethics and Framework](#) for working with funding partners

Full details of EPF's funding available at our website: www.eu-patient.eu/About-EPF/Transparency/

Our Strategic Goals (2014-2020)



Health Literacy



Healthcare Access & Quality

- Health/social services
- Medicines
- Cross-border healthcare
- Patient safety



Patient involvement



Patient Empowerment

- Patient-centred practices
- Clinical trials
- eHealth...



Sustainable Patients' Organisations



Non-discrimination

Adherence: relevance for EU policy



Adherence is relevant for tackling the “sustainability challenge”

Should be a priority at EU level – policy and research

EPF: link between adherence and patient-centred practice, patient empowerment & involvement

Adherence on EPF's agenda



European Federation of Pharmaceutical Industries and Associations



“Improving the sustainability of healthcare systems through better adherence to therapies: a multi-stakeholder approach ”

Background briefing

Introduction: why does adherence matter?

“Drugs don't work in patients who don't take them”¹ – as the former U.S. surgeon general C. Everett Koop said. However, policy makers, health managers and healthcare professionals often underestimate the opportunity to improve health outcomes and rationalise health expenditure through monitoring what happens after a medicine has been prescribed. The issuing of a prescription is the first step towards safe and high-quality pharmacotherapy; however, it is estimated that 20% to 30% of patients do not adhere to medication regimens that are curative or relieve symptoms, and 30% to 40% fail to follow regimens designed to prevent health problems. When long-term medication is prescribed, 50% of patients fail to adhere to the prescribed regimen.²

2011:
Joint awareness-
raising seminar –
European
Parliament
EPF, PGEU, CPME
& EFPIA

Adherence on EPF's agenda

Figure 1: the competency framework for managing and supporting medication adherence with patients

COMMUNICATING WITH PATIENTS ABOUT MEDICATION	
1. LISTENING <i>Listen actively to the patient</i> <ol style="list-style-type: none"> 1. Helps patients feel at ease and feel that you have time for them 2. Gives the patient the opportunity to express their views 3. Listens to the patient's views and discusses any concerns 4. Encourages the patient to ask questions about their condition 5. Allows time for questions 6. Treats the patient as an equal partner 7. Respects diversity 8. Expresses willingness to be flexible 	2. COMMUNICATING <i>Helps patients to interpret information in a way that is meaningful to them</i> <ol style="list-style-type: none"> 1. Identifies barriers to communication and responds appropriately 2. Shares knowledge and information in a way that the patient understands 3. Explores and confirms the patient's understanding 4. Checks own understanding of the patient's viewpoint 5. Uses aids to help understanding (e.g. decision aids and question prompts) 6. Recognises the importance of non verbal communication and responds appropriately 7. Uses questions to elicit information 8. Maintains appropriate eye contact 9. Displays a non judgemental attitude
3. CONTEXT <i>With the patient, defines and agrees the purpose of the consultation</i> <ol style="list-style-type: none"> 1. Reviews patient information prior to the consultation 2. Introduces and explains own role 3. Establishes how involved the patient wants to be in decisions about their treatment 4. Clarifies the timing, boundaries and expectations of the consultation 5. Ensures that the consultation takes place in an appropriate setting and minimises interruptions 6. Keeps focused on the agreed aims of the consultation 	4. KNOWLEDGE <i>Has up-to-date knowledge of areas of practice and wider health and social services</i> <ol style="list-style-type: none"> 1. Knows own limitations 2. Maintains up-to-date professional knowledge and skills appropriate to own role 3. Knows when and how to seek further advice 4. Refers on to other health professionals and social services as required or as requested 5. Works in partnership with colleagues 6. Shares up-to-date information with patients about specialist support and community resources 7. Is aware of practical resources to help patients
MANAGING AND SUPPORTING MEDICATION ADHERENCE	
5. UNDERSTANDING <i>Recognises that the patient is an individual</i> <ol style="list-style-type: none"> 1. Seeks to understand the patient's current circumstances and previous experiences (including, for example, age, gender, disability, mental health, literacy, health literacy and socioeconomic status) that may impact on treatment 2. Is aware of whether the patient's cultural, religious or societal beliefs impact on treatment 3. Explores what the patient thinks about medicines in general 4. Respects the patient's expertise and knowledge of their condition 	6. EXPLORING <i>Discusses illness and treatment options, including no treatment</i> <ol style="list-style-type: none"> 1. Explores what the patient has been doing to deal with symptoms / illness and what the patient understands about their treatment 2. Discusses with the patient their expectations and concerns about their illness and treatment 3. Provides full, accurate and understandable information about the patient's symptoms / illness and the benefits, effects, risks (e.g. side effects) and uncertainty of all treatment options 4. Discusses prognosis and likely health outcomes 5. Establishes whether the health professional and the patient have similar or different views about the patient's symptoms / illness 6. Discusses any misunderstandings about illness or treatments 7. Encourages the patient to express positive and negative views about treatment and no treatment options
7. DECIDING <i>Decides with the patient the best management strategy</i> <ol style="list-style-type: none"> 1. Discusses the patient's preferred option for treatment, negotiates treatment goals and decisions, but accepts the patient's final decision 2. Gives the patient time to consider the information before making a decision, if appropriate 3. Maintains appropriate professional records about decisions that are made and their outcomes 4. Explores the patient's ability to undertake the agreed plan 5. Checks that the patient knows what medicines they are taking and why 6. Discusses when treatment will be reviewed (and what this entails), changed or stopped 7. Ensures that the patient knows what to do if their symptoms change, do not improve, or if a problem arises (e.g. a side effect) 	8. SUPPORTING <i>Supports the patient with medication taking</i> <ol style="list-style-type: none"> 1. Recognises non-adherence (identifies patients at risk of non-adherence, assesses patients' adherence, for example by asking if they have missed any doses of their medication, and recognises the effects of non-adherence) 2. Identifies reasons for / causes of non-adherence, and barriers to future adherence 3. Manages adherence by providing effective practical support where the patient needs / wants help with adherence 4. Supports patients by providing ongoing information and feedback (including encouraging patients to come back with any questions), and monitors adherence
<ul style="list-style-type: none"> Managing and supporting medication adherence with patients may also involve others, e.g. family members, carers and advocates Health professionals clearly need a wide and variable range of competencies in their consultations with patients. This framework concentrates on the competencies that any health professional might need when engaging with patients in managing and supporting medicines adherence and should be used in conjunction with other professional and organisational frameworks 	

ABC (Ascertaining Barriers to Compliance) project, FP7 2009-2012

Publication: educational framework for health professionals

<http://abcproject.eu/index.php?page=publications>

Adherence on EPF's agenda

- 2015: EPF position paper on Adherence and Concordance
- Sets out the views of our members
- Recommendations for professionals, policy makers, researchers, European Commission



Adherence and Concordance

EPF Position Paper

March 2015

EPF principles on adherence and concordance

1. Strategies to promote adherence should be based on the concept of concordance and encompass health literacy, user-friendly information, and shared decision-making by patient and health professional.
2. Patients should not be blamed for non-adherence or forced to adhere.
3. Patients should be supported with all possible means to adhere to their (appropriate) treatments, or to change treatment if desired, through regular medication reviews.
4. Patients' personal goals – life goals as well as treatment goals – should guide the treatment decision. Treatment should be tailored to individual patients' needs, and doctors should always elicit the patient's preferences.
5. Communication about medicines should be based on full and comprehensive information, be accessible and tailored for individual patients as well as specific groups, such as older patients and patients with low health literacy.
6. High-quality, easy-to-understand information about medicines, including their benefits and risks, should be easily accessible, e.g. through online portals.
7. Health professionals should work in integrated teams with effective flow of information, especially during handovers/transitions.
8. Self-management support (e.g. CDMP courses, peer-led support services) should be integrated into all chronic disease-management programmes.
9. eHealth and mHealth adherence support tools should be developed with patients' identified needs as the starting point and with patient involvement from the outset.
10. R&D on new treatments should specifically address the concept of concordance and adherence support. Patient representatives should be meaningfully involved in designing research and prioritising topics for research.

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A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

Adherence describes “the extent to which the patient’s behaviour matches the agreed recommendations from the prescriber”

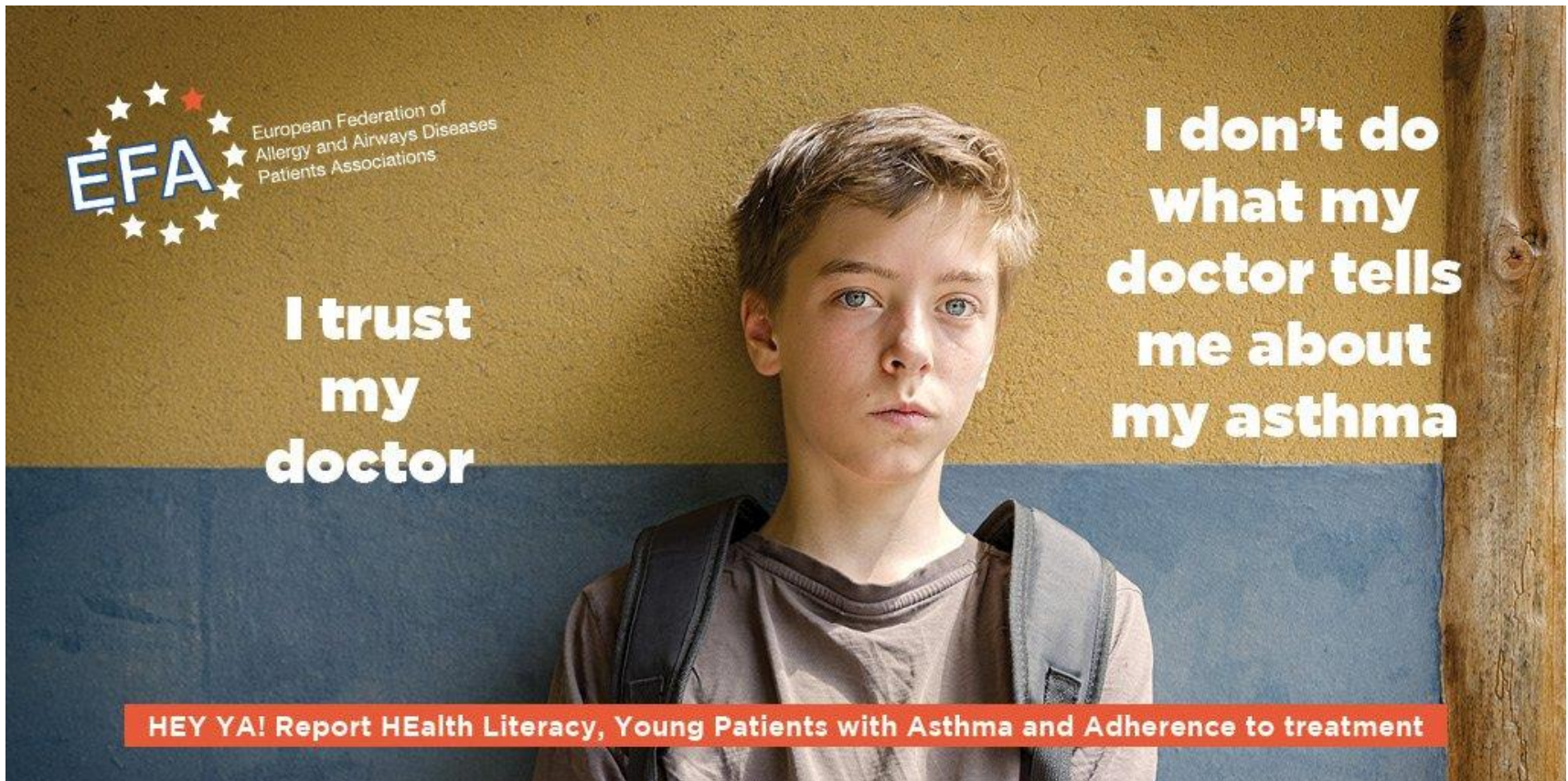
- Preferable to “compliance” – implies need for agreement between doctor and patient; failure to adhere should not be a reason to blame the patient

Concordance focuses on the patient-prescriber relationship and the degree to which the prescription represents a shared decision. In a concordant process, the beliefs and preferences of both the prescriber and the patient are taken fully into consideration. It can also refer to a wider concept of patient support in medicine taking.

- Informed choice and partnership/therapeutic alliance

Why are patients not adhering?

Literature: reasons for non-adherence are varied and multifactorial; both intentional and unintentional



EFA European Federation of Allergy and Airways Diseases Patients Associations

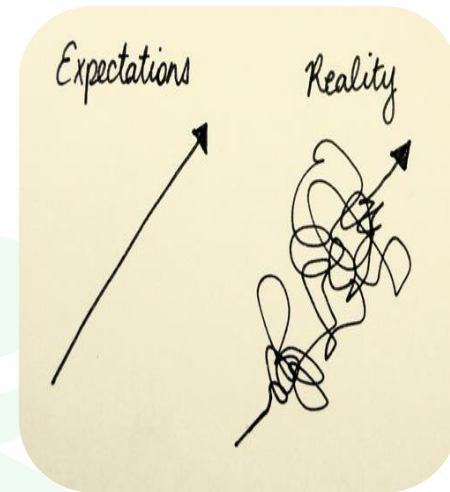
I trust my doctor

I don't do what my doctor tells me about my asthma

HEY YA! Report HEalth Literacy, Young Patients with Asthma and Adherence to treatment

Complexities of living with a chronic condition were often mentioned by respondents to our consultation:

- Complexity of treatment
- The burden of treatment on everyday life
- Lack of opportunity to have a proper discussion with professionals



“People with chronic diseases often have to dedicate significant time, energy and resources to dealing with multiple medical appointments and treatments... negative impact on quality of life overall.”



A study by EPF member ALLIANCE (Scotland) found:

Older patients/those with multiple chronic conditions experience disjointed services

Each specialist focuses on their “own” condition → patients have little support to manage interactions and “the whole”

“The majority of people who do not adhere to treatment report that they do not have the capacity, skills and knowledge to do so, which would indicate a greater need for self-management support.”

“Listening to [the patients’] experience offers valuable insight, advice and support to help improve services.”

Prescription for Excellence: A Vision and Action Plan for the right pharmaceutical care through integrated partnerships and innovation” at www.scotland.gov.uk/Resource/0043/00434053.pdf

Other factors were mentioned:

- Impact of the financial crisis, increases in out-of-pocket costs
- Shortages of health professionals
- Shortages of medicines

Impact of financial factors is particularly felt by the older and the poorer patients

Patients acutely aware of the pressures their health systems are under



Caveat from some patient groups

- Adherence not always felt to be a positive concept
 - Mental health field: power relation, autonomy, right to refuse treatment
 - Many prefer non-pharmacological approaches or combination treatments involving therapy
 - Critique of the biomedical approach to mental health
- Over-medication, inappropriate medication also a problem
 - Polypharmacy and complex conditions

- Strategies to increase adherence should focus on **health literacy** and **empowerment**, together with appropriate systems to support patients
 - Well informed patients are better equipped to be partners in care
- Implementing patient-centred healthcare, including shared decision-making is essential
 - Shared decision-making is a core aspect of empowerment (EMPATHIE, 2014)
- Health professionals need to engage with patients as equal partners, really listening to and taking account of their views
 - This can present a challenge to the professionals

Patient empowerment is *a process* that helps patients gain control over their lives, increasing their capacity to act on issues that *they themselves* define as important

... a process through which patients *individually and collectively* are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and take action to meet those needs.

(Adapted from JA-PaSQ, 2012)

- A process – non-binary, non-linear
- Capacity to be in control of what happens to you
- Cannot be imposed from top-down – needs changes at all levels

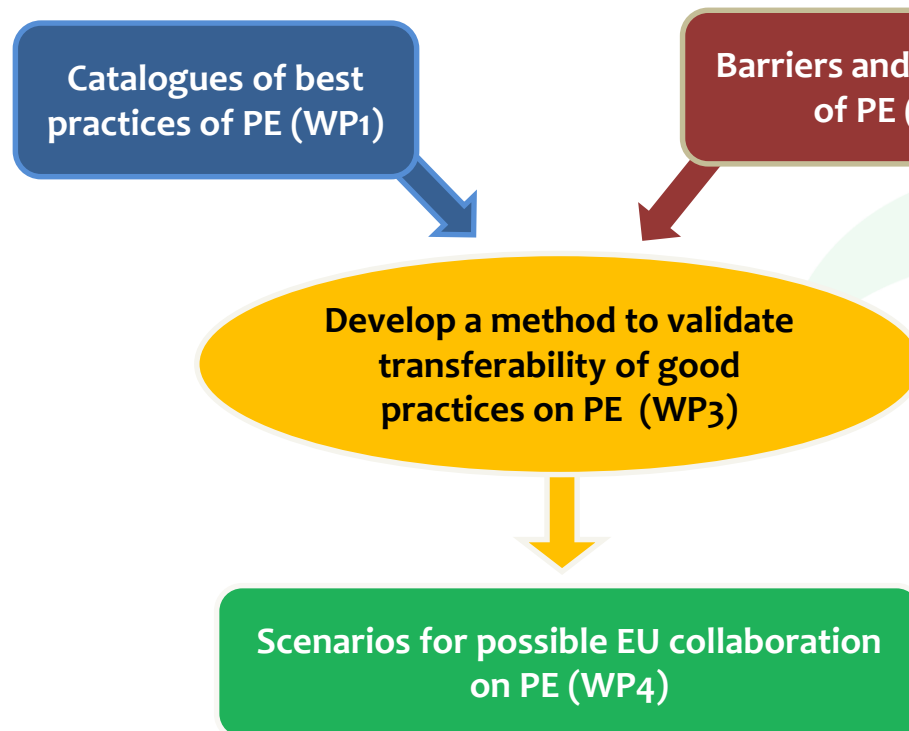
“An empowered patient has control over the management of their condition in daily life. They take action to improve the quality of their life and have the necessary knowledge, skills, attitudes and self-awareness to adjust their behaviour and to work in partnership with others where necessary, to achieve optimal well-being.

Empowerment interventions aim to equip patients (and their informal caregivers whenever appropriate) with the capacity to

- participate in decisions related to their condition to the extent that they wish to do so;
- to become “co-managers” of their condition in partnership with health professionals; and
- to develop self-confidence, self-esteem and coping skills to manage the physical, emotional and social impacts of illness in everyday life.” (EMPATHIE, 2014)

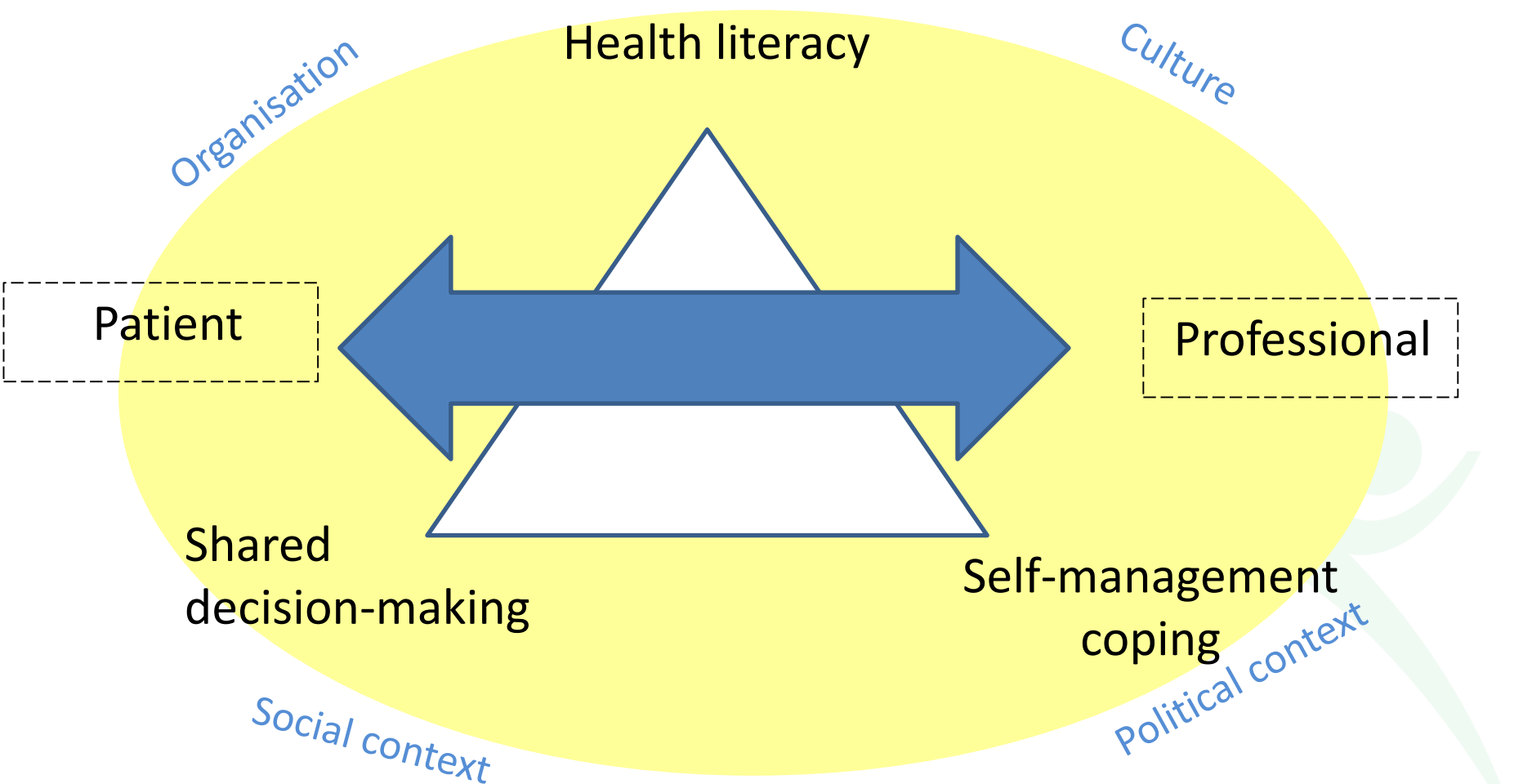
EMPATIE “Empowering PATients in Their Health management In Europe” (EAHC tender no. EAHC/2013/Health/04)

Final report: Sept 2014



- Avedis Donabedian Research Institute (FAD), Barcelona
- Dutch Institute for Healthcare Improvement (CBO)
- European Patients' Forum (EPF)
- Chalmers University of Technology, Sweden
- Masaryk University, Czech Republic
- Danish Committee for Health Education
- Royal College of Psychiatrists, UK
- Standing Committee of European Doctors (CPME)

EMPATHiE: aspects of empowerment



Adapted from EMPATHiE project (2014)

How to improve adherence?



1. Information and Health Literacy



2. Shared decision-making, CONCORDANCE

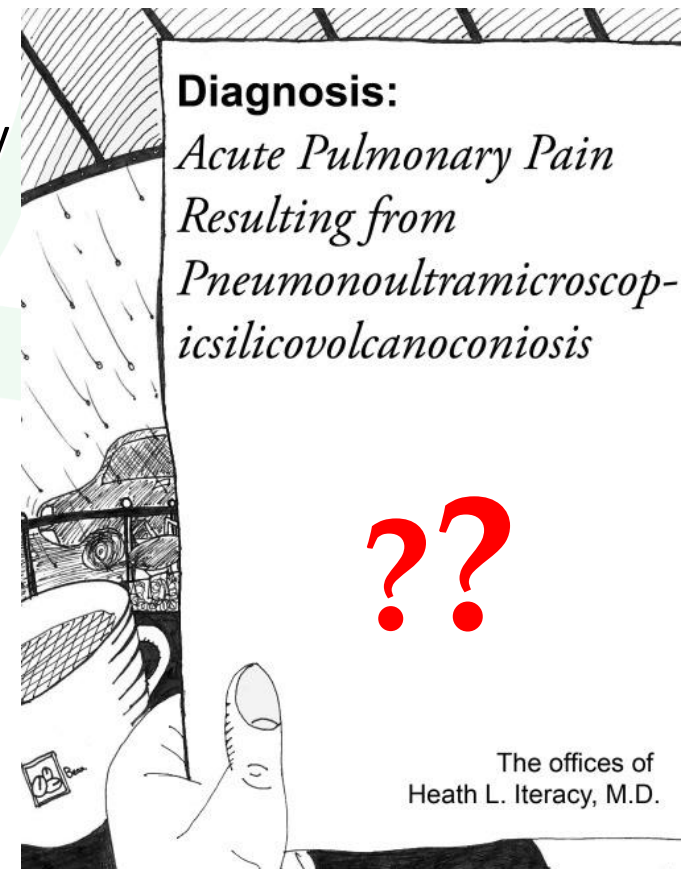


3. Professionals' training

- Critical points: treatment decision, prescribing, starting on a new medicine, any changes...
- Ongoing information needs over time
- Information sources include all HCP – community be better harnessed
- Health literacy should be addressed

“The information ... should be *discussed* rather than presented, making sure that the patient understands the treatment and has an opportunity to express concerns that may arise also after reading the package information leaflet.”

- Patient



How to improve adherence?



1. Information and Health Literacy

THE PATIENTS KNOW MORE ABOUT THEIR DISEASES THAN ME. I MUST GET FASTER MODEM, HIGHER SPEED INTERNET ACCESS THAN THEM



2. Shared decision-making, CONCORDANCE

training



3. Professionals' training

- Change in consulting style, deeper understanding of patients' beliefs, experience and knowledge
- Engage with patients as valued partners, respect their beliefs and concerns
- Approach the patient as a whole person, not only a medical problem
- Patient's life goals matter – not just medical outcomes
- Drs and patients need to recognise the uncertainties of different treatment options

© Randy Glasbergen
www.glasbergen.com



"You have to learn about thousands of diseases, but I only have to focus on fixing what's wrong with ME! Now which one of us do you think is the expert?"

Key barriers mentioned by our members:


- Lack of time to discuss with patients
- Attitudes of professionals
- Workload, resulting in “overloaded” professionals
- Lack of training
- Lack of incentives for providing therapeutic education and advice
- Stigma, particularly in mental health conditions

“Long-standing tradition of paternalism and lack of motivation to change”



Skills, knowledge and attitudes:

- “Really” listening to the patient
- Empathy
- Respect
- Communication skills
- Training to assess patients properly
- Asking the right questions
- An open mind



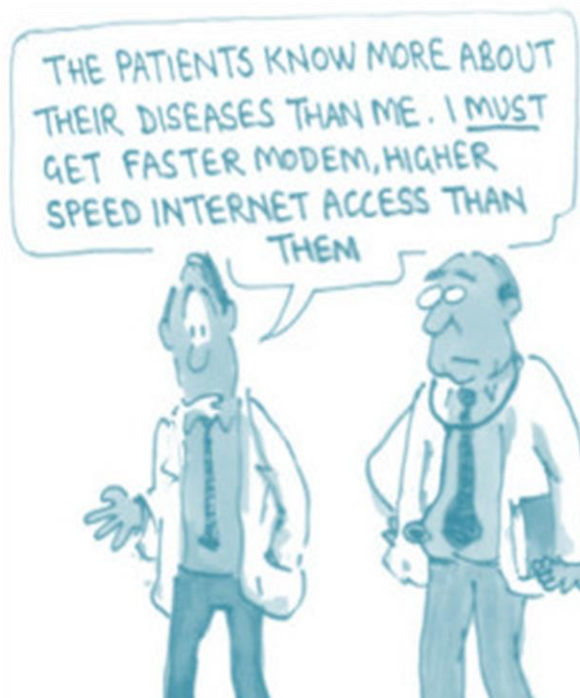
“It is important for professionals to *believe* that involving patients in decision-making promotes trust and honesty and leads to better outcomes”

How to improve adherence?

Information, communication → a shared decision



1. Information and Health Literacy



2. Shared decision-making, CONCORDANCE



3. Professionals' training

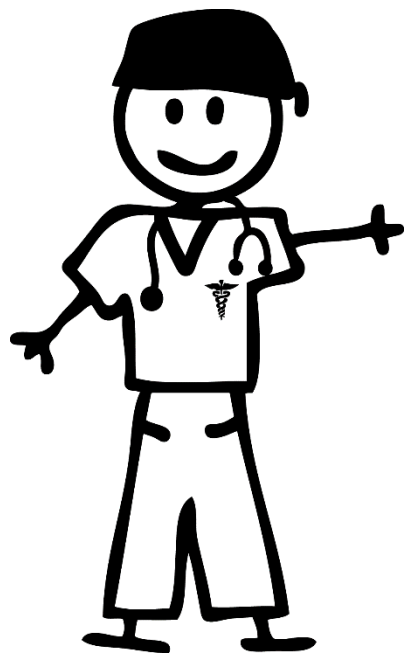
- HCP attitudes = major barrier to empowerment (EMPATHIE)
- BUT also need to change the practice of current professionals
- “From God to guide”
- Top-down policy (healthcare organisations...) and bottom-up change (peer leaders...)

“Pressure from organisation’s management to ensure that shared decision-making is adopted at every level could help – especially in countries where the doctor-patient role is rather old-fashioned .”



How to improve adherence?

Integrated self-management support



4. Ongoing, integrated support system



5. Use of appropriate technology tools



6. Patient reporting of adverse events

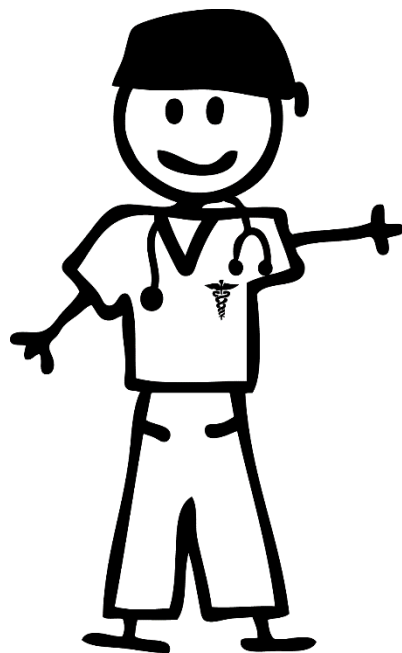
Ongoing, integrated support

- “Joined-up care” approach
- All professionals play a role – particularly pharmacists, nurses who are often closer to the patient than doctors
- Roles of non-medical professionals – psychologists, social workers, therapists...
- Peer support (e.g. through patient organisations)



How to improve adherence?

Integrated self-management support



4. Ongoing, integrated support system



5. Use of appropriate technology tools



6. Patient reporting of adverse events

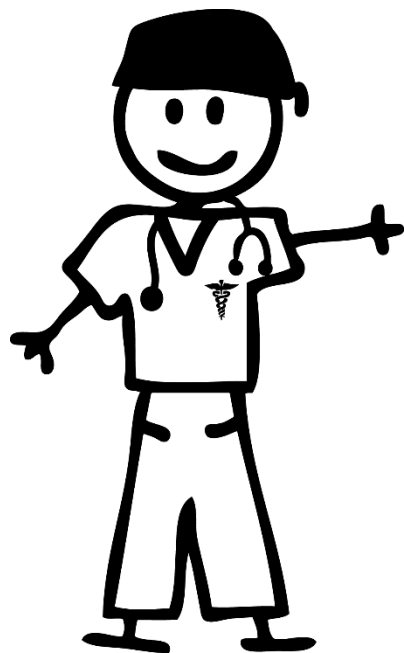
Use of appropriate technology tools

- mHealth solutions could be useful for some patients
- Technology *in itself* is not empowering – needs to be embedded within an integrated care approach
- Tools need to be co-designed with patients to ensure they provide real solutions
- Access and co-ownership of one's own health data – the cornerstone of empowerment



How to improve adherence?

Integrated self-management support



4. Ongoing, integrated support system



5. Use of appropriate technology tools



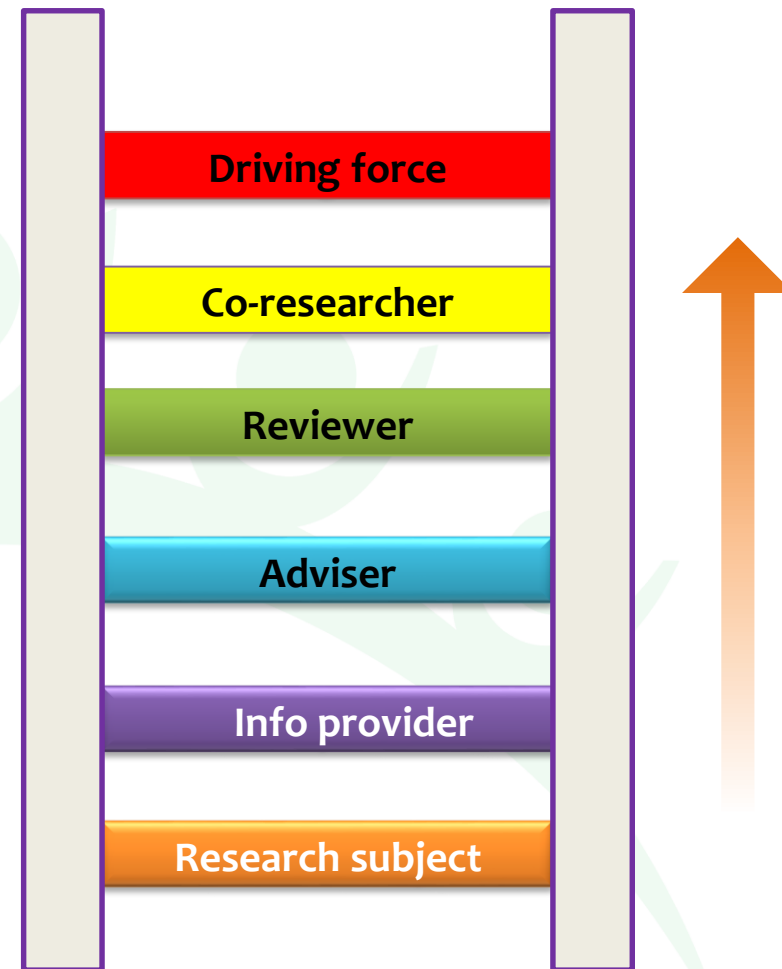
6. Patient reporting of adverse events

- Adverse reactions (ADRs) – or fear of them – major adherence factor AND also a big problem: 5th cause of deaths in hospital...
... yet only 10–25% of all ADRs are reported*
- Increasing patient reporting → an opportunity to improve adherence and medicines safety
- New EU rules bring better opportunities for patients to report – but how well are they implemented across the EU?
- Knowing I can report suspected ADRs also directly to the Regulator... knowing these reports are valued... makes me more aware as a patient and helps in honest discussion of side effects

* European Commission, http://ec.europa.eu/health/files/pharmacovigilance/qa_pharmacovigilance_2011_en.pdf

Patient organisations play a role

- Peer support
- Understanding their communities
- Information “by patients, for patients”
- Advocacy for patient-centred health services & policy
- Developing and sharing good practices
- Collaboration with HCPs and academia



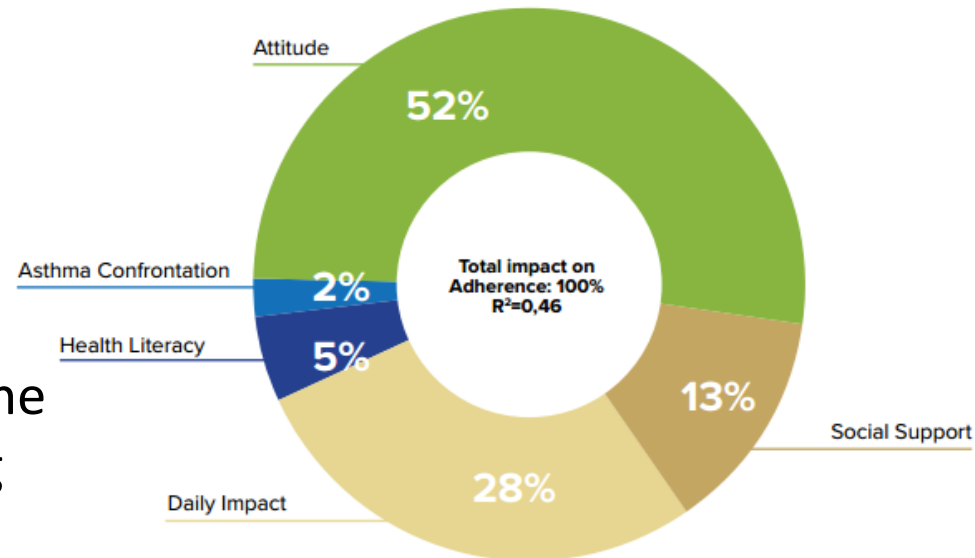
PatientPartner FP7
Project (2010)

Example: EFA “HEY YA!” project

- Interviews with 200 adolescents
- Listen to what they had to say!
- ‘Attitude’ and ‘Daily impact of asthma’ key explaining factors:
 - Forgetfulness
 - Rebellion
 - Good days
 - Support from treating doctor
 - Carelessness
 - Ignoring impact of nonadherence
- Future research should focus on the attitudes and behaviours of young people



Figure 10: Touch Points for Adherence
(adapted from the original GfK report)



Courtesy of EFA. More information:

http://www.efanet.org/images/2016/EFA_Report_HEY_YA_Health_Literacy_Young_Patients_with_Asthma_and_Adherence_to_Treatment_2016_April.pdf

From our position paper
“Adherence and Concordance” (2015)



Professional education & training

- a. Training in shared decision-making integrated into all medical training and continuous professional education
- b. Existing patient-centred tools should be implemented and used in professional education
- c. Common set of professional competences for patient-centred healthcare at EU level, with patient involvement and with tools for adaptation to different national and professional contexts

Good practice sharing

- d. Good practices in concordance should be identified, implemented and integrated into the care pathway. The Innovation Partnership on Active and Healthy Ageing can be used as a platform.

Information for patients

- e. Implement and/or further develop National Medicines Information portals (EU pharmacovigilance legislation) with involvement of patient organisations to ensure that information is relevant, easily understandable, accessible and useful
- f. Action to improve user-friendliness of package information leaflets (PIL)

Access and health inequalities

- g. Explore the impact of the financial crisis on adherence and in EU initiatives around health inequalities and access to medicines.

Support for patient organisations

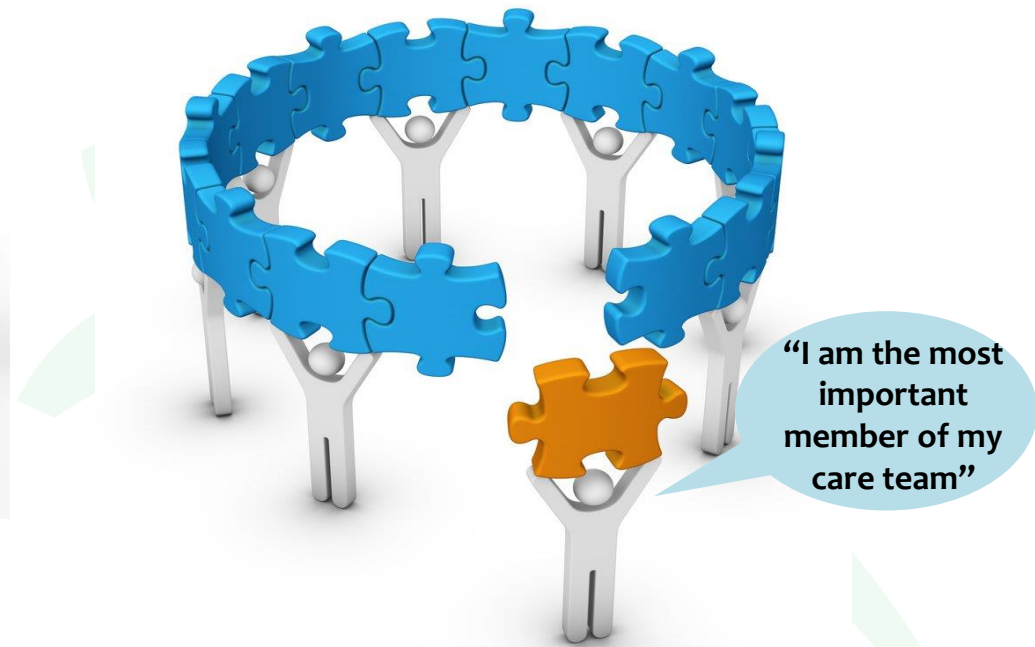
- h. Patient organisations, peer and self-help groups should be involved in developing advocacy strategies and providing information
They should be sustainably resourced to carry out their functions

Research

- i. Existing knowledge from EU-funded research should be taken forward to implementation
- j. EU Health Programme and Horizon 2020 should prioritise studies on educational and training pathways on how to involve patients in treatment – targeted at physicians/pharmacists/nurses and patients

In conclusion

From doing things “to” the patient...



... to doing things WITH the patient!

EPF Campaign on Patient Empowerment

Patient's Charter on Patient Empowerment (2016)



INDIVIDUAL

EDUCATION

Patients can make informed decisions about their health if they are able to access all the relevant information needed, in an easily understandable format.



EXPERTISE

Patients self-manage their condition every day so they have a unique expertise on healthcare which needs to be supported.



EQUALITY

Patients need support to become equal partners with health professionals in the management of their condition.



ORGANISATIONAL

EXPERIENCE

Individual patients work with patient organisations, to represent them, and channel their experience and collective voice.



POLICY

ENGAGEMENT

Patient need to be involved in designing more effective healthcare for all, and in research to deliver new and better treatments and services.



The Patients' Charter on Patient Empowerment

1. I am more than my health condition
2. I am empowered to the extent I wish to be
3. I am an equal partner in all decisions related to my health
4. I have the information I need in an easily understandable format, including my own health records
5. My health professionals and our health system actively promote health literacy for all
6. I have the ongoing support I need to manage my own care
7. My experience is a vital measure of healthcare quality
8. I can participate in evaluating and co-designing healthcare services so they work better for everyone
9. Through patient organisations, my voice becomes part of a bigger, united voice
10. Equity and empowerment go hand-in-hand - I want a fair deal for all patients

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This campaign is a joint initiative of the European Patients' Forum and the Robert Bosch Stiftung with the support of Amgen, GSK and MSD.

Robert Bosch Stiftung

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