
The European Patients' Forum
Strategic Plan
2014-2020



**WHO WE ARE.
WHAT WE STAND FOR.
HOW WE WORK.**
*A clear blueprint on our strategic
direction and aspirations over the
next seven years.*

Contents

Foreword	4
Executive Summary	5
1. Purpose and Development of the Strategic Plan 2014-2020	6
Purpose of this Document	6
Strategic Planning Process	6
Mid-Term Review.....	7
2. Trends and Developments that Will Affect the Patients' Community over the Next Years	8
Economic Factors	8
Political Factors.....	9
Technological/Scientific Factors	11
Socio-Cultural.....	13
3. Critical Strategic Issues	14
EPF'S Development	14
Broadening EPF's Field of Action beyond Healthcare.....	14
Primary Prevention	14
Patients vs. Persons with Chronic Conditions.....	14
Informal Carers	15
A More Explicit Reference to the Rights of Patients.....	15
Patients' Responsibility.....	15
Giving a Voice to Under-Represented Patients	15
Reference to Mental Health	15
Reinforcing the Link between the EU and the Member State Levels.....	16
Capacity Building.....	16
4. Who We Are and What We Stand For	17
Mission and Vision	18
EPF's Core Values	18
Patient-centred	18
Non-Discrimination	18
Health Equity.....	18
Health in all Policies	18
Empowering Patients.....	18

Consultative	19
Independent and Transparent	19
Inclusive	19
5. Strategic Goals	20
6. Action Fields.....	21
Field of Action 1 - Communications and Campaigning	21
Field of Action 2 - Patients' Experience and Expertise to Substantiate EPF'S Policy and Project Work.....	21
Field of Action 3 - Dialogue and Cooperation with the EU Institutions, Member States' Governments and other Key Institutions by.....	22
Field of Action 4 - Key Strategic Partnerships and Alliances with.....	22
Field of Action 5 - Broadening and Consolidation of the EPF Membership and Strengthening their Involvement in EPF and in EU-level Cooperation	23
7. Review and Realignment	24
Glossary.....	28
Acknowledgements.....	35

Foreword

Since our creation in 2003 and the establishment of the secretariat in 2006, the European Patients' Forum has grown in recognition and influence in providing the patients' perspective in EU healthcare debates. During this period, the healthcare environment has significantly changed bringing new challenges and opportunities.

Development and Mid-Term Review

In order to reflect this evolution and as it approaches the end of its original seven-year Strategic Plan (2007-2013), the European Patients' Forum (EPF) decided to develop a new Strategic Plan 2014-2020 which covers the new EU Programming period.

In 2017, after three years of implementation, this Strategic Plan 2014-2020 was reviewed in order to integrate the latest changes in the European health and social policy environment and to incorporate new challenges and opportunities for EPF as an umbrella of patient organisations active across Europe.

Objectives of the Document

This plan describes who we are, what we stand for and what we want to achieve. It provides a clear blueprint of the strategic direction of the organisation over seven years, resulting from the contribution of the whole EPF membership.

Patients and the patient community are called upon to play a new and different role than in the past. We are more and more key actors and contributors to build future health systems that are patient-centred, high quality and sustainable. We hope that this plan reflects the proactive role we are keen to play.

We also hope readers will find this document useful in understanding our organisation and cementing opportunities for working with us for the benefits of all patients across the EU.

Executive Summary

The EPF Strategic plan 2014- 2020 consists of nine sections.

1. Purpose and development of the Strategic Plan 2014-2020: provides a description of the purpose of a seven-year Strategic Plan for EPF, and the process through which this plan was developed and will evolve during the coming seven years.

2. Trends and developments that will affect the patient community over the next seven years: describes the current prevailing healthcare environment as well as trends for the coming years.

3. Critical strategic issues: gives an overview of the issues that shaped reflections and discussions during the strategic planning process. They provide the background behind the defining of EPF vision, mission, values and strategic goals.

4. Who we are and what we stand for: describes EPF's core values and guiding principles and outlines EPF's vision for the future and its mission.

5. Strategic Goals: describes EPF's strategic goals for the coming seven years.

6. Fields of Action: defines the fields of action that will support the achievement of the strategic goals.

7. Review and Realignment: outlines the strategies for process and outcome evaluation and how the Strategic Plan will be refined in accordance with on-going review of achievements and challenges, and the external environment. It also provides key performance indicators.

8. Glossary: provides definitions for terms linked to this Strategic Plan.

9. Acknowledgements: lists the individuals who have played a key role in the development of the Strategic Plan.

1. Purpose and Development of the Strategic Plan 2014-2020

PURPOSE OF THIS DOCUMENT

The purpose of the Strategic Plan is two-fold:

- It defines who we are, what we stand for and how we work;
- It provides a clear blueprint on our strategic direction and aspirations over the next seven years.

This document was reviewed in 2017 to be realigned in accordance with internal and external developments during the course of the seven year-period which it covers.

STRATEGIC PLANNING PROCESS

As we were approaching the end of our original seven-year Strategic Plan (2007-2013), the European Patients' Forum (EPF) decided to initiate a debate that would lead to the development of a new Strategic Plan covering the 2014-2020 period.

The strategic planning process was undertaken according to a participatory approach whereby the entire membership was involved at different stages.

A Strategic Plan seminar held in April 2012 represented the first step of this process. EPF members had the opportunity to review what was accomplished in recent years in relation to the strategic goals established back in 2007 and identify new challenges. A working group consisting of nine representatives from a cross section of the EPF membership was set up to spearhead this work.

The seminar launched a reflection process regarding possible future goals, strategic directions and issues around the organisation's development.

The outcomes were consolidated in a blueprint that was revised several times based on the input provided by the following groups:

- Working Group of EPF members
- EPF Board
- EPF Policy Advisory Group
- EPF Youth Group
- EPF Secretariat

Two consultations were conducted with the entire membership between February and May. The final Strategic Plan was endorsed at the Annual General Meeting in May 2013.

MID-TERM REVIEW

In 2017, after three years of implementation, this Strategic Plan 2014-2020 was reviewed in order to integrate the latest changes in the European health and social policy environment and to incorporate new challenges and opportunities for EPF as an umbrella of patient organisations active across Europe.

The environmental analysis which constitutes the introduction to EPF's current Strategic Plan was reviewed and expanded by external consultants, to be as objective as possible. It is available as a separate document.

The revision of EPF's Strategic Priorities as laid out in this document constituted a three-fold process. Input was provided by the Secretariat, by the Board of EPF, and by the members. More precisely, during this consultation process, we were looking at identifying:

- The current trends and developments that will affect each of the thematic areas EPF is working on;
- The stakeholders relevant for our activities, and how they can interact with us;
- The extent to which we have progressed towards each strategic goal and thematic area against the key performance indicators we set ourselves in 2013;
- Potential new priorities and actions.

2. Trends and Developments that Will Affect the Patient Community over the Next Years

We feel that the environmental analysis below, written in 2013 at the time of development, is still largely valid. To complement it, and to take stock of the developments in EPF's external environment between the first draft of this Strategic Plan and 2017, a revised situational analysis was performed from April to July 2017.

This environmental scan, developed by external consultants, outlines the factors that shape and affect the current and future activities of the European Patients' Forum: economic factors, political factors – including (but not exclusively focusing on) health and social policy developments –, technological/scientific factors and socio-cultural factors.

In addition to the complementary situational analysis report, some minor modifications have been made to the original text.

The revised situational analysis is available as a separate document here:

<http://www.eu-patient.eu/globalassets/library/strategic-planning/situational-analysis-october-2017.pdf>

ECONOMIC FACTORS

The *economic downturn* may persist, with a continuing negative impact on health and social budgets of European countries. Even a return to growth is unlikely to have a corresponding effect on the available health budgets; moreover, the impact of the financial crisis will continue to be felt for some years ahead.

Healthcare costs are increasing faster than the economy can currently keep up with.¹ Thus, economic considerations will feature prominently in the political discussions around health and healthcare reforms.

European countries are facing the challenge of an *ageing population*. People aged 65 and over are the fastest growing segment of the population, and this age group is projected to grow to more than 25% of the total population of the European region by 2050.² As the general population is ageing, many chronic diseases become more prevalent, and patients with chronic diseases developed at a younger age are living longer thanks to modern medical treatments. As persons with chronic diseases age and older people acquire chronic diseases and co-morbidities, they develop specific needs and are confronted with unique difficulties in addition to facing obstacles common to patients with chronic

¹ Josep Figueras and Martin McKee, *Health systems, health, wealth and societal well-being. Assessing the case for investing in health systems* (World Health Organisation, 2011), at http://www.euro.who.int/__data/assets/pdf_file/0007/164383/e96159.pdf

² The European health report 2012. WHO regional office for Europe, 2013. Available at <http://www.euro.who.int/en/what-we-do/data-and-evidence/european-health-report-2012>

diseases of all age. These difficulties can be socio-cultural, medical, related to patient safety or other issues.³

On the other hand, investing in health represents an opportunity for economic growth. Appropriate investment in health systems is an effective way of improving health and wealth by saving lives, creating societal wellbeing, and supporting healthier and therefore more economically active societies.⁴ Increasing the efficiency as well as effectiveness of healthcare, including avoiding overmedicalization and inappropriate treatment as well as undertreatment, and investing in better preventive approaches can also reduce healthcare costs and improve European citizens' health.

*Citizens continue to prioritise health as their top concern⁵, and so far, clearly continue to support universality and solidarity in healthcare. Moreover, the objective of the EC Active and Healthy Ageing Partnership⁶ has been to add, by 2020, two healthy life years to the average healthy life span of European citizens. But Member States are increasingly under pressure to cut healthcare costs. They have to decide how best to *balance the need to provide high-quality healthcare for all, while maintaining the sustainability of the healthcare services.* Cost-benefit assessment (e.g., through Health Technology Assessment) is becoming an essential element in the development, approval and reimbursement of new treatments. Patients' access to the latest innovative therapies is being increasingly questioned on economic grounds based on the significant increases in the prices of certain medical treatments recently authorized in Europe, the cost of which becomes threatening to become unsustainable for many healthcare systems.⁷*

Increased out-of-pocket payments or cuts in coverage have had serious consequences for some patients, who may forgo treatment for financial reasons, thus putting their health at greater risk.

POLITICAL FACTORS

EU competence in health continues to be restricted by the Treaty of the European Union⁸. Thus, the organisation of health systems and delivery of healthcare remain Member States' competencies. *EU-level collaboration in the area of health* was seen to increase over the last decade, driven by Member States' recognition of its added value to address major challenges faced by all EU countries, such as demographic ageing, chronic diseases and concerns over the sustainability of national health systems.

The third EU health programme – “Health for Growth” (2014-2020) – linked EU health policy objectives directly to economic growth and sustainability questions along the lines of the *Europe 2020 strategy*

³ EPF position statement on the rights and needs of older patients, December 2013. Available at http://www.eu-patient.eu/globalassets/policy/ageing/epf_position-paper_older-patients_jan14.pdf

⁴ Josep Figueras and Martin McKee, *Health systems, health, wealth and societal well-being. Assessing the case for investing in health systems* (World Health Organisation, 2011), at http://www.euro.who.int/_data/assets/pdf_file/0007/164383/e96159.pdf

⁵ “The value which Europeans say is the most important to their happiness is health (75%, +2 percentage points since the EB69 survey of spring 2008), a long way ahead of the other items”, Standard Eurobarometer 77, Spring 2012 at http://ec.europa.eu/public_opinion/archives/eb/eb77/eb77_value_en.pdf

⁶ https://ec.europa.eu/eip/ageing/home_en

⁷ EPF (2016) “Core Principles from the Patients' Perspective on the Value and Pricing of Innovative Medicines”

⁸ <http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:12012M/TXT>

for smart, inclusive and sustainable growth. Thus, health is acknowledged as a crucial component for reaching the goals of Europe 2020. However, in the last two years, the trend of increasing collaboration has reversed at the political level: health has been de-prioritised by the Juncker Commission, and whilst many Member States still appreciate the added-value of collaboration, others are increasingly opposed to what they see as excessive Commission interference.

The real implications of Brexit for patients, both within the EU and in the UK, are not yet fully known. The relocation of the EMA has been the first ‘milestone’.⁹ The patient community has voiced the need to ensure the smoothest possible transition and to put patient safety and medicines’ efficacy at the forefront. Aside from the regulatory environment impacts will be seen in health research and innovation cooperation, reciprocal health insurance arrangements, and movements of healthcare workforce in Europe.

There is a recognition that *current European health systems are outdated, and ill-equipped to meet future challenges*¹⁰, but currently there is no consensus as to what kind of system is “best”. The aim of all reforms is to address chronic disease management and prevention and contain costs, while continuing to provide citizens with high-quality healthcare. *Migration of health professionals* across the EU has led to shortages in some Member States. New types of health professionals are needed, with new skills, including technology and patient-centred skills.

The focus of EU health debates has shifted more and more towards *health promotion and primary prevention*, with citizens and consumers often being referred to as the main target group in this context rather than “patients” (even though patients are citizens). This can be both an opportunity for patients with chronic and lifelong conditions as effective prevention can free resources for patient care, and also since effective prevention can contribute to better quality of life for patients with chronic diseases), and a challenge (a main policy focus on primary prevention may have the unintended consequence of marginalising the needs of patients with chronic diseases).

The debate on *health inequalities*, also, has centred largely on social determinants of health affecting whole population groups, rather than healthcare provision specifically or inequities affecting patients. Yet health inequalities affect patients particularly, and reforms of health systems may either alleviate or worsen them. Recently, there has been greater recognition of the need to measure access to healthcare as part of health systems’ performance.

At EU level, *patients are well-established as a legitimate and valued stakeholder group*. EPF is recognised as the prime representative organisation across chronic diseases. The Commission is increasingly consulting citizens on new policies, and requests for input are received on an increasing number of diverse policy areas – touching on health either directly or indirectly.

Patients’ rights are established and patient organisations set up and strengthened in many Member States. However, there are still important gaps particularly in enforcement of patients’ rights. Patient

⁹ See joint letters here, here and here

¹⁰ Ellen Nolte, Martin Mc Kee, *Caring for people with chronic conditions, a health system perspective*, World Health Organization 2008, p2 at http://www.euro.who.int/__data/assets/pdf_file/0006/96468/E91878.pdf

involvement in policy-making is still controversial, and there is a gap between the EU and national level in the extent to which patients and patient organisations are involved in health-related policies.

Patient-centeredness is recognised as one of the “common operating principles” of European health systems. However, in practice its application varies across the EU. Indeed patient-centred care is often approached superficially, focusing on consumer “choice” and “satisfaction”, with user feedback as a tick-box exercise. An important barrier to real implementation of patient-centred healthcare is the lack of a common understanding of what this really means (for patients). Patient-centeredness is one of the key principles of high-quality healthcare as defined by the WHO. EPF has long advocated for patient-centeredness to be measured as part of health system performance; in 2017 an initiative was launched by the OECD with EU funding to develop appropriate indicators for patient-reported outcomes and patient experiences; EPF will be actively involved in this process.

While universal access to high-quality care is a well-recognised goal for all healthcare systems in the EU, this is not yet a reality for all patients in the EU. EPF’s 2017 Campaign on Access to Healthcare for All calls on Member States and the EU to commit to a long-term vision on equity of access and universal health – a target of the third UN Sustainable Development Goal on ensuring healthy lives. A resulting Roadmap will conclude this campaign, identifying the political actions that EU decision-makers and Member States need to take in order to achieve universal health coverage for all patients in the EU by 2030. *The impact of key EU ‘hard’ legislation* will become clearer in the next years, with the implementation of major directives on cross-border healthcare, pharmacovigilance, falsified medicines and clinical trials. The implementation and transition periods are lengthy, but they may lead to greater empowerment of patients and affect the patient-health professional relationship (e.g. direct patient reporting). The impact of soft law (e.g. recommendations and communications) is harder to predict.

TECHNOLOGICAL/SCIENTIFIC FACTORS

Digital health, including eHealth will continue to be a priority area of EU health policy. eHealth records controlled by the patient and technologies such as personalised remote monitoring devices and novel communication solutions have the potential to empower patients to take control of their own healthcare and play an active role in the patient-health professional relationship. Nanotechnology, especially nanodevices – non-invasive devices to monitor individual persons’ health status – may be developed to use in personalised healthcare.

Personalised medicine – also sometimes referred to as stratified or precision medicine – is likely to be a major driver of research and ICT development – while information technology innovations will in turn be a major driver of personalised medicine. Rapidly increasing knowledge of the mechanisms of disease, and the genetic and other differences between individuals and populations, are predicted by some to lead to a “paradigm shift” in medicine: a shift from curative to pre-emptive, and from disease-centred to person-centred. This is a gradual process likely to take at least 20 years if not more; it is difficult to predict and riddled with uncertainty. Personalised medicine has the potential to make treatment more precise, reduce side effects, and generate savings in healthcare through eliminating needless prescriptions. However, the very high cost of personalised medicine is one of the main

barriers in the take-up of these technologies. Scientific developments will have political, legal, economic and ethical implications across the whole healthcare spectrum. Patient groups need to keep a keen eye on these developments. The EU Framework Programme for research and innovation, Horizon 2020¹¹, includes personalised medicine as a priority area. Other relevant EU initiatives include the European Innovation Partnership on Healthy and Active Ageing, and the Innovative Medicines Initiative (IMI).¹²

Future biomedical and public health research, the development of personalised medicine, and eHealth have implications for the *use of patients' data*. There is increasing recognition that medical data needs to be more widely shared. Furthermore, personalised electronic health records may in future contain genomic and lifestyle data. Legal and ethical issues include for example privacy and confidentiality, informed consent, use of individual data for research, access to patient data by e.g. insurers, and discrimination based on health status/genetic profile.

The *pharmaceutical industry* is facing the end of the “blockbuster” era as many major medicines come to the end of their market exclusivity period. Entry to the market of new generics and biosimilar medicines is leading to lower prices and increasing treatment options. Consequently, industry is transforming its business model to take account of genomics and personalised medicine, and therapies are being developed for highly specific, small patient sub-groups. Meanwhile, the concept of *adaptive pathways* is being developed to accelerate access to new medicines in areas of high medical need¹³. While controlled clinical trials are in some cases no longer the only or best way to test new therapies, adaptive pathways have caused concern that if they become widespread this will lead to a lowering of the level of evidence generally required for the approval of new medicines in the EU market. The increase in specialty therapies is seen as one key factor in the increasing costs of healthcare and a threat to the sustainability of health systems (OECD, 2017), leading to debates around the value of innovation, societal preferences and the need for more transparency about the costs of medicines research. In these debates, patients and the public play different and complementary roles, and the involvement of patient organisations in the policy debates and relevant processes on access and added value (e.g., design of clinical studies, selection of endpoints...) is vital.

Health literacy, including e-literacy and scientific literacy, and meaningful, systematic patient involvement are crucial to realising technological innovation in a way that meets patients' needs. *Patients' expertise*, which is based on their experiential knowledge, is starting to be recognised as equally valid and complementing scientific knowledge. Patient input into research and development is an opportunity to develop new treatments and technologies that better meet patients' needs and are also cost-effective.

¹¹ <https://ec.europa.eu/programmes/horizon2020/>

¹² <http://www.imi.europa.eu/>

¹³ There is no commonly accepted definition of adaptive pathways. It generally refers to a medicines development process that is both flexible and iterative in nature and encompasses the entire life-cycle of a therapy. See the glossary for further information.

SOCIO-CULTURAL

Communication technology is a major driver of patient empowerment and networking. Patients are able to access more and more information and communicate rapidly with each other and with health professionals. The “e-patients” phenomenon from the US and Canada is spreading to Europe. *Empowered, informed patients are driving a cultural shift* in the patient’s and health professionals’ role. The “e-patients” advocate for a “participatory medicine” model where networked patients become responsible drivers of their health, and in which healthcare providers encourage and value them as full partners.

The patient movement has grown enormously in the recent years. On the other hand, *patients are still sometimes regarded with scepticism* – often seen as “driving up healthcare costs” by demanding expensive treatments, despite increasing evidence that engaged patients actually contribute to lowering costs as well as improving quality of healthcare.¹⁴ Tackling chronic diseases and implementing innovative solutions such as personalised medicine and eHealth, imply a need for patient involvement. In future, patient involvement will no longer be an optional choice but a must.

Patients therefore have an opportunity to become truly a part of the solution in the creation of future healthcare systems by *demonstrating the value of patient involvement*. On the other hand, with the focus on health promotion and prevention, health is increasingly seen at EU level as concerning citizens and populations, not only patients.

We are seeing also tendencies towards a more *consumerist approach to health* – an increased focus on “well-being”. The well-being concept is being stretched by commercial providers to encompass for example certain cosmetic medical procedures, nutritional supplements etc. presenting health increasingly as a lifestyle issue. Consumerism combined with the idea that lifestyle factors can cause various chronic diseases, is shifting discussions towards “individual responsibility” over one’s health. Moreover, “patient choice” (interpreted as choice of provider) is a key driver in many healthcare reforms. Health literate/informed patients and citizens will be expected to take good care of their health, thus cost less to the healthcare services. Chronic diseases, however, do not only result from lifestyle factors. In the medium to longer term and under the current economic circumstances, there is a risk that patients may increasingly be stigmatised for having a disease and thus considered a burden on healthcare resources and requested to bear the costs themselves. Choice, if applied in purely market terms without the necessary supporting elements of patient empowerment, such as health literacy and increased transparency of the health system, can increase the burden on patients and potentially deepen inequities.

¹⁴ Mieke Rijken, Martyn Jones, Monique Heijmans and Anna Dixon, *Chapter 6: Supporting self-management* in Ellen Nolte, Martin Mc Kee, *Caring for people with chronic conditions, a health system perspective*, World Health Organization 2008, p116-138; Patient-centred care models have been shown to be cost-effective as well as increase patient satisfaction and often clinical outcomes: “A cost-effectiveness study of a patient-centred integrated care pathway”, *J Adv Nurs*, Aug; 65(8); “*Stop the silent misdiagnosis: patients’ preferences matter*” *British Medical Journal*, 2012, Number 245; Coulter A, Ellins J. “Effectiveness of strategies for informing, educating and involving patients”, *British Medical Journal*, 2007, 335:24–27

3. Critical Strategic Issues

A series of issues drove reflections and discussions during the strategic planning process. We describe them here to provide the background behind the defining of EPF's vision, mission, values and strategic goals.

EPF'S DEVELOPMENT

EPF has changed significantly since the adoption of the first Strategic Plan back in 2006, in terms of:

- **Capacity**, e.g. number of members (from 24 to 74), paid staff (from three to 15), and annual turnover (from 3.000 EUR to approximately 1.500.000,000 EUR);
- **Activities**, e.g. projects (from zero to five running in 2017 with a leading role in three of them); policy dossiers (over 20), as well as increased presence in major health-related events;
- **Impact**, as shown by the growing recognition of patients as key stakeholders in EU-health policies, programmes and projects.

BROADENING EPF'S FIELD OF ACTION BEYOND HEALTHCARE

The notion of “holistic approach” has evolved over time to include social care as well as patients' interaction with the wider environment – public services, employment, education, youth policies, etc.

We debated whether EPF should get actively involved in topics that are not directly related to healthcare provision. The direction defined is that EPF should keep healthcare as its core focus in order to maximise the impact of our work. However, EPF will seek cooperation with organisations whose mandate is to work on those policies and programmes that affect other aspects of a patient's life than health.

PRIMARY PREVENTION

A key discussion point was whether EPF should engage in primary prevention and the health promotion agenda. Considering EPF's remit to represent the interests of patients with chronic and/or lifelong conditions, the conclusion was the EPF should not, but we will reinforce our role in secondary and tertiary prevention.

PATIENTS VS. PERSONS WITH CHRONIC CONDITIONS

It was noted that the word patient could be misleading or misinterpreted by the general public, as many people usually use it to refer to any individual using a healthcare service regardless of whether he/she has a chronic condition.

Through the mission and vision, it should be clear for a person who comes across EPF for the first time that our constituency consists primarily of people who have been diagnosed with a chronic and/ or lifelong condition. Preliminary discussions on EPF's Patient Empowerment Working Group have been

favourable towards using the term "person-centred" in parallel to patient-centred, to emphasise the fact that patients are individual persons with lives beyond their health status.

INFORMAL CARERS

The notion of informal carers is intended to indicate families, relatives and friends of a patient. The question debated was whether EPF should make a more explicit reference to informal carers in its mission and vision, or whether this should not be mentioned as our main target is patients. The position agreed was to integrate this in other parts of the Strategic Plan. EPF has also developed a closer working relationship with the EU-level organisation representing informal carers.

A MORE EXPLICIT REFERENCE TO THE RIGHTS OF PATIENTS

Although EPF's work has always been driven by a patients' rights approach, this did not appear explicitly in the past Strategic Plan. It was therefore agreed to make appropriate changes to bring this to the fore in a clear manner. EPF has focus on patients' rights as part of our work on cross-border healthcare and initiated an internal paper on patients' rights and responsibilities in 2016, which is being developed further with the membership.

PATIENTS' RESPONSIBILITY

Including a reference to "patients' responsibilities" was also debated. There is a risk that this could increase stigmatization of patients; however, there is broad agreement among working groups that it is appropriate to address responsibilities. Our position, therefore, is to integrate this issue in the forthcoming paper on patients' rights, emphasising the positive elements and linking it to the empowerment concept and ensuring that patients' rights can never be challenged on the basis of their alleged responsibilities.

GIVING A VOICE TO UNDER-REPRESENTED PATIENTS

As patient organisations develop a stronger voice, there may be a risk of marginalising those who are not normally represented in them, and do not have a voice. We decided to explicitly commit to reaching out under-represented patients (e.g. regular or irregular migrants, ethnic minorities). In 2016 EPF initiated a process to take this forward with our membership and in liaison with NGOs representing these groups.

REFERENCE TO MENTAL HEALTH

EPF members from the mental health community pointed out that EPF should make explicit reference to mental health in its vision and mission. Other members believe otherwise, because the word "patient" already encompasses people with mental conditions. Mental health specific issues are within the remit of mental health organisations, while EPF should maintain a clear cross-disease character. Further discussions indicated that we should not make an explicit reference to it, but the links between physical and mental health, including the notion of the impact of the disease on patients' psychological status, should be mainstreamed in all EPF work.

REINFORCING THE LINK BETWEEN THE EU AND THE MEMBER STATE LEVELS

Despite the principle of subsidiarity, the EU and national-level health policy environments are more and more interlinked and need to build synergies. There is clearly an opportunity for EPF to contribute building these synergies through its membership by fostering sharing of good practices and cross-fertilisation. Through the capacity-building programme and through our policy work, inter alia regarding the implementation of EU policies and recommendations, we empower patient communities to get involved in advocacy in their national context.

CAPACITY-BUILDING

EPF has greatly intensified its capacity-building activities in order to strengthen the patient movement. It was decided to emphasise this capacity-building role in the Strategic Plan.

4. Who We Are and What We Stand For

EPF:

- Was set up in 2003 to represent the collective interests of patients in the EU with a main focus on chronic and/or lifelong conditions, demonstrating the solidarity, commitment and unity of the patients' movement across the EU;
- Conveys the patients' and their informal carers' unique experience and expertise through representative member organisations bringing together national, regional and local patient organisations across Europe;
- Adopts a holistic and patient-centred approach by focusing primarily on the patients' experience of healthcare while building alliances with other actors to ensure that all core issues in a patient's life are addressed effectively;
- Drives and advances the patients' rights agenda by acting both as a catalyst for positive change in EU health systems and a watchdog;
- Is a credible and expert partner for cooperation and dialogue with a broad range of stakeholders in the EU and internationally;
- Promotes the building and sharing of patient-centred good practice;
- Engages actively in developing the capacity of patient organisations at EU and national levels to channel their expertise and knowledge in order to be effective actors in the healthcare arena;
- Represents the collective expertise of a large, diverse membership through which it builds a bridge between the EU and Member States' policies and programmes;
- Welcomes as its members European and national umbrella patient organisations that fulfil criteria relating to legitimacy, representation, democracy, accountability and transparency;
- Is a rights-based, apolitical, representative advocacy organisation with governance bodies composed of elected non-paid representatives of members, supported by a professional secretariat of paid staff.

MISSION AND VISION

Following the mid-term review of the EPF Strategic Plan, in consultation with EPF members, and reflecting the profound political changes that happened in Europe since the original drafting of the Strategic Plan, EPF's vision and mission have been slightly updated:

Our **Vision** is that ***all patients with chronic conditions in Europe have access to high-quality, patient-centred health and related care.***

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 equitable patient access to care in Europe.***

EPF'S CORE VALUES

PATIENT-CENTRED

We are driven by a rights-based, patient-centred approach to health and social care policies that affect patients and their informal carers in the EU.

NON-DISCRIMINATION

We promote patients' rights for all patients regardless of health status, age, sex, ethnic origin, political belief, religious conviction, marital status, economic status, sexual orientation, gender identity or any other factor that could lead to discrimination.

HEALTH EQUITY

We believe every patient should have equitable access to patient-centred, high-quality health and social care, and we strive to fight the disparities existing within the EU in relation to access to and standards of care for chronic diseases and lifelong conditions.

HEALTH IN ALL POLICIES

We promote a 'health in all policies' approach to ensure the multiple vulnerabilities of patients and the physical and psychological impact of their condition are properly addressed, including inability to work, direct and indirect costs of illness, loss of income and risk of poverty, social exclusion, discrimination and stigma.

EMPOWERING PATIENTS

We advance the empowerment of patients and their informal carers by fostering positive attitudes and the development of support policies and programmes that enable them to make informed choices and have their place in society as equal citizens.

CONSULTATIVE

We bring a unique patients' perspective by enabling all our member organisations to contribute their distinctive expertise and wealth of knowledge to influence the programmes and policies that have an impact on patients across the EU.

INDEPENDENT AND TRANSPARENT

We are an independent organisation, transparent in all our operations - financial, policy, communications.

INCLUSIVE

We are an open and inclusive organisation that strives to ensure that our work reflects the needs of all patients and their informal carers, including those who are under-represented.

5. Strategic Goals

Goal 1: Health Literacy

To promote access for patients and their informal carers to information and education that enables them to make informed choices about their health.

Goal 2: Healthcare Access and Quality

To contribute to improvements in health systems that enable equitable access to sustainable and high-quality healthcare designed and delivered to meet patients' and informal carers' needs at all levels of care, embracing innovation in all its forms.

Goal 3: Patient Involvement

To advance meaningful patient involvement in the development and implementation of health-related policies, programmes and projects in the EU.

Goal 4: Patient Empowerment

To promote the development and implementation of policies, strategies and healthcare services that empower patients to be involved in the decision-making and management of their condition according to their preference, whilst raising awareness about their rights and responsibilities.

Goal 5: Sustainable Patient Organisations

To support the development, growth and capacity of inclusive, effective, sustainable and representative patient organisations and to foster cooperation and synergies between them.

Goal 6: Non-Discrimination

To promote the development of EU and national policies that tackle discrimination faced by patients in health and social care as well as in domains like education and employment.

6. Action Fields

This section of the Strategic Plan describes in general terms the fields of action EPF will focus upon to work towards the strategic goals identified. They are often related to the advancement of more than one strategic goal.

These fields of action give a sense of the approach and methodology we will pursue in the coming years. They are generic in nature and will be defined precisely in our Annual Work Plans.

The fields of actions are numbered, not in priority but for ease of reference.

FIELD OF ACTION 1 – COMMUNICATIONS AND CAMPAIGNING

- Developing effective, high-quality and targeted communication tools for both internal and external use;
- Lead/support at least one high-profile media and political campaign per annum focusing on a thematic priority agreed by the membership;
- Ensuring high-level presence and constructive input at relevant health events.

FIELD OF ACTION 2 – PATIENTS’ EXPERIENCE AND EXPERTISE TO SUBSTANTIATE EPF’S POLICY AND PROJECT WORK

- Mapping and exploiting effectively existing materials, documentation and tools on patients’ rights, patient-centred health and social care, patient involvement and empowerment;
- Leading and engaging in quantitative and qualitative research on patients’ rights, patient-centred health and social care, patient involvement and empowerment;
- Collecting evidence on patients’ direct experiences across Europe;
- Placing specific emphasis on initiatives aiming at including the voices of under-represented and or socially-excluded patients in EPF’s work;
- Working in cooperation with appropriate research networks to enhance knowledge on patients’ experience for campaign and policy work on patients’ rights, patient-centred health and social care and empowerment;
- Mapping and making visible the specific areas where patients face discrimination on the grounds of health status – such as social, economic, educational, etc.

FIELD OF ACTION 3 – DIALOGUE AND COOPERATION WITH THE EU INSTITUTIONS, MEMBER STATES’ GOVERNMENTS AND OTHER KEY INSTITUTIONS BY

- Developing and sustaining advocacy work and policy capacity;
- Building relationships/profile with European Commission Directorates and relevant officials in the spirit of health in all policies and specifically the integration of social care and healthcare, with particular emphasis on pro-active discussions to influence, rather than simply reaction to pre-set agendas;
- Establishing champions in the European Parliament across all the political groups (MEPs and Secretariat staff);
- Fostering strong relationships with Member States’ permanent representations/health attachés, and national ministries of health;
- Developing and implementing a long-term approach to influence the EU Council Presidency Trios;
- Developing and agreeing position papers and ‘lines to take’ on potential future EU health topics important to patients in order to ensure rapid, consolidated responses if and when needed;
- Building relationships with other institutions that influence EU health and social care developments, for example WHO-Europe, OECD and the European Observatory;
- Contributing to advancing the ‘Framework Directive on Discrimination’, also to include discrimination on the grounds of health status.

FIELD OF ACTION 4 – KEY STRATEGIC PARTNERSHIPS AND ALLIANCES WITH

- Other umbrella health and social NGOs and networks (including the International Alliance of Patient Organisations, the European Public Health Alliance);
- EU Agencies, primarily the European Medicines Agency (EMA), Fundamental Rights Agency (FRA) and the European Centre for Disease Prevention and Control (ECDC);
- EU level health professional organisations (including CPME, PGEU, EFN, UEMS) and professional societies;
- Health and social/economics research organisations and academic networks;
- Health agencies, alliances, think tanks and informal networks;

- The European Social Platform to contribute to selected campaigns linked to discrimination and to acquire a better understanding on how to engage with marginalised/underrepresented groups and patients therein;
- Constituency-based NGOs with an interest in health (for example AGE Europe and the European Disability Forum) and those working on social inclusion and with vulnerable groups (for example PICUM and FEANTSA);
- Other health-related partners (eHealth/digital health, pharmaceuticals, health equipment and medical devices, industry federations).

FILED OF ACTION 5 – BROADENING AND CONSOLIDATION OF THE EPF MEMBERSHIP AND STRENGTHENING THEIR INVOLVEMENT IN EPF AND IN EU-LEVEL COOPERATION

- Bridging the work that we undertake in a specifically EU context with EPF members’ work and collaboration in the wider Europe;
- Scaling up the EPF Capacity Building Programme for our member organisations who request it, and their members. This focuses on organisational development and EU patient advocacy;
- Involving members effectively in ‘growing’ EPF and its member organisations through well-structured consultation and sharing of information, know-how and good practices;
- Creating thematic working groups to lead on specific policy issues that advance our strategic goals and operational objectives, with the support of the EPF Secretariat, enabling the Secretariat, the Board and the Policy Advisory group to focus primarily on 3-4 core areas agreed by our membership;
- Exploring the opportunities and possible avenues for EPF to expand its membership beyond the EU to neighbouring and EEA countries;
- Engaging with national patient forums or coalitions that bring together national representative patient organisations to work strategically on EU healthcare policy and influence their respective governments, with EPF’s support, if requested;
- Engaging existing members as ambassadors and recruiters of new EPF members;
- Implementing specific actions aimed at fostering active and meaningful involvement of young patients in patient organisations at both European and national level. At EPF level, exploring the opportunity to include a member of the Youth Group as a voting member of the EPF Board;
- Strengthening the relationship between the EUPATI community and EPF as the host organisation. Identifying modes and processes to utilise the EUPATI alumni expertise in EPF’s work;

- Involving potential new members in joint policy initiatives or projects.

7. Review and Realignment

EPF will undertake on-going monitoring and evaluation of the Strategic Plan in line with agreed measurable performance indicators and targets for each core strategic goal. The evaluation of the 2014-2020 Strategic Plan will be an integral part of EPF Annual Work Plans' evaluation process. Accordingly, at the end of each year achievements *vis-à-vis* indicators and targets set out for each core strategic goal will be measured with a view to assessing incremental progress against those goals.

Although the Strategic Plan's evaluation will draw on findings of evaluation conducted against specific operational objectives set out in the various implementing annual work plans, key processes and milestones stretching over several years (e.g. advocacy work, EU projects, EPF Capacity Building Programme, communication strategy, etc.) will be followed through from inception to final delivery and beyond to measure their short, medium, and long-term impact and inform our work and direction accordingly.

Monitoring and evaluation will be carried out internally by the EPF Secretariat. In order to ensure transparency and independence, internal evaluation will be complemented by external evaluation looking more specifically into some key processes and milestones and exploring aspects such as perception of relevance of EPF work among our constituency and external stakeholders, overall effectiveness and efficiency of EPF strategies, approaches and working methods, as well as synergy between EPF policy advocacy, programmes and projects.

The EPF Board will be involved regularly in reviewing and appraising evaluation findings with a view to ensuring that evaluation findings and recommendations are acted upon in a prompt manner.

Strategic Plan evaluation will also involve EPF constituency at large, i.e. EPF members as well as lay patients and informal carers, external stakeholders, i.e. health professional associations, industry players, academia as well as media and policy makers.

A mid-term assessment of progress made against strategic goals was undertaken in 2017. To that end, additional specific evaluation activities involving EPF constituency and all relevant external stakeholders were put in place and specific recommendations were made.

EPF is committed to this approach in order to be able to demonstrate how we do business and how we deliver in the context of the Strategic Plan in question and the various Annual Work Plans implementing it, but also in order to plan, anticipate, and be as proactive and effective as possible as a lead organisation in the EU health policy environment.

The following performance indicators will be used to assess progress against strategic goals. For each multiannual and annual work programme, specific indicators will be defined based on these broader ones.

GOAL 1: Health Literacy

To promote access for patients and their informal carers to information and education that enables them to make informed choices about their health.

Key performance indicators:

- EPF is successful in ensuring health literacy is a priority within EU and national level health strategies, policies and projects;
- EPF is successful in highlighting the importance of health literacy-friendly communication, inter alia by promoting the use of Core Quality Principles¹⁵ on information for patients for any health-related issues provided by different stakeholders in the health arena.

GOAL 2: Healthcare Access and Quality

To contribute to improvements in health systems that enable equitable access¹⁶ to sustainable and high-quality healthcare designed and delivered to meet patients' and informal carers' needs at all levels of care, embracing innovation in all its forms.

Key performance indicators:

- EPF is successful in influencing priority-setting and advising EU policies in such a way that these are conducive to addressing real patients' needs more effectively;
- Through its members, EPF is successful in ensuring that the process of transposition and implementation of relevant EU legislation is as patient-centred as possible;
- EPF is successful in contributing towards identifying solutions to make national healthcare systems more sustainable while preserving and strengthening health services' quality, safety and equitable access for all patients;
- EPF is successful in contributing to promoting greater patient involvement in the healthcare sector to ensure innovation and the digitalization of healthcare, while safeguarding patients' data from privacy and security concerns and providing solutions to patients' real needs and expectations, including those with low health literacy.
- EPF is successful in bringing the patients' perspective to the European discussion on the impact of medicines' affordability and availability on patients' access to the care they need.

GOAL 3: Patient Involvement

To advance meaningful patient involvement in the development and implementation of health-related policies, programmes and projects in the EU.

Key performance indicators

¹⁵ [“Core quality principles for patient information on diseases and treatment options”, High-Level Pharmaceutical Forum, 2008. Available at <http://ec.europa.eu/DocsRoom/documents/7593?locale=en>;](http://ec.europa.eu/DocsRoom/documents/7593?locale=en) Methodology of use document available at <http://ec.europa.eu/DocsRoom/documents/7594?locale=en>

¹⁶ See EPF definition of access in the glossary at the end of this document.

- EPF is successful in promoting active and effective involvement of patient organisations in policy-making at EU level;
- EPF is successful in promoting active and effective involvement of patient organisations in European projects and initiatives;
- Through its membership, EPF is successful in contributing to strengthening the involvement of patient and patient organisations in national-level policy-making.

Goal 4: Patient Empowerment

To promote the development and implementation of policies, strategies and healthcare services that empower patients to be involved in the decision-making and management of their condition according to their preference, whilst raising awareness about their rights and responsibilities.

Key performance indicators:

- EPF is successful in highlighting the critical role played by patients in managing chronic conditions and how empowered patients can contribute to high-quality, sustainable healthcare systems;
- EPF is successful in raising policy-makers' and stakeholders' awareness of what patient empowerment means from the patient perspective;
- EPF is successful in promoting patient empowerment as a policy priority at European level;
- EPF and its membership are successful in promoting and sharing good practices in patient empowerment at all levels in the healthcare system.

Goal 5: Sustainable Patient Organisations

To support the development, growth and capacity building of inclusive, effective and sustainable representative patient organisations and to foster cooperation and synergies between them.

Key performance indicators:

- EPF is successful in identifying good-practices and promoting development and implementation of strategies for involving patients in decisions making and management of their condition in partnership with healthcare professionals and according to their preference for active engagement;
- EPF is successful in contributing to identifying and raising awareness of patient rights and responsibilities arising from patients' more active involvement in decisions making and management of their condition.

Goal 6: Non –Discrimination

To promote the development of EU and national policies that tackle discrimination faced by patients in health and social care as well as in domains like education and employment.

Key performance indicators:

- EPF is successful in promoting equal treatment for patients with chronic diseases, gathering evidence and raising awareness of discrimination of patients with chronic conditions in

healthcare, employment and education as a result of their disease, while sustaining efforts to prevent discrimination;

- EPF is successful in promoting the recognition of health status/ chronic disease as a specific ground of discrimination and paving the way for the inclusion of chronic disease within the scope of non-discrimination legislation at EU and national level.

Glossary

Access	<p>Access is comprised of 5 dimensions, referred to as the “5 As of access” .</p> <p>Availability – whether a healthcare service or product is provided by one’s health system;</p> <p>Affordability – whether seeking healthcare causes financial hardship to patients;</p> <p>Accessibility – whether there are barriers that stop patients from accessing healthcare;</p> <p>Adequacy – which refers to the quality of healthcare;</p> <p>Appropriateness – whether healthcare meets the need of different groups of the population.</p> <p>(EPF (2015), “Defining and Measuring Access to Healthcare: the Patients’ Perspective”) http://www.eu-patient.eu/globalassets/policy/access/epf_position_defining_and_measuring_access_010316.pdf, retrieved: 11 October 2017)</p>
Adaptive Pathways	<p>There is no commonly agreed definition for adaptive pathways. The European Medicines Agency sees it as “a scientific concept for medicine development and data generation which allows for early and progressive patient access to a medicine”. It is thus an approach that uses the tools that already exist under the EU regulatory framework – including scientific advice; compassionate use; conditional approval (for medicines addressing life-threatening conditions); patient registries and other pharmacovigilance tools – that allow collection of real-life data and make it possible to develop an optimal risk-management plan for each medicine. Adaptive pathways is not a new regulatory route for authorisation of medicines.</p> <p>The IMI ADAPT-SMART project describes an essential aspect of adaptive pathways as the “upfront acknowledgement of the need for additional learning and putting in place a plan for post-licensing knowledge generation – this is a “life-span approach” to learning.... The licence and reimbursement conditions of a product will be re-assessed and revised as more knowledge is gained. This is what is meant by an “iterative development and assessment plan”. (ADAPT-SMART website)</p>
Advocacy	<p>Is seeking to affect some aspect of society, or promote a cause or principle, through education, research, information and public engagement. EPF focuses on advocacy around patients’ rights, the safety and quality of healthcare, recognition of the importance of the patient’s perspective, etc.</p>
Apolitical	<p>Not affiliated to any particular political party.</p>
Advocacy campaign	<p>A campaign is linked to a single, definable policy / political goal usually with a very specific time-line.</p>
Capacity building (for non-profit organisations)	<p>Refers to activities that improve and enhance a non-profit organization’s ability to achieve its mission and sustain itself over time. Examples include: identifying a communications strategy; improving volunteer recruitment; adopting new governance practices; identifying more efficient uses of technology; and engaging in collaborations with community partners. When capacity building is successful, it strengthens a non-profit’s ability to fulfil its mission over time and enhances the organisation’s ability to have a significant, positive impact on lives and communities.</p> <p>(National Council of Non-profits, http://www.councilofnonprofits.org/public-policy/federal-issues/nonprofit-capacity-building, retrieved: 5 April 2013)</p>
Chronic diseases	<p>Refers to “diseases of long duration and generally slow progression”</p> <p>(World Health Organisation, http://www.who.int/topics/chronic_diseases/en/)</p>
Discrimination	<p>Prejudicial or distinguishing treatment of individuals based on their actual or perceived membership in a certain group or category, such as their race, gender, sexual orientation, gender identity, national origin, ethnicity, religion, disability, age, or other characteristics.</p>

	<p>Healthcare discrimination: partial or total ban from access to preventive healthcare and the right to benefit from medical treatment under the conditions established by national laws and practices, based on different grounds.</p> <p><i>(adapted from Article 21 of the Charter of Fundamental Rights of the European Union, 2000, http://www.europarl.europa.eu/charter/pdf/text_en.pdf).</i></p>
Disease prevention: primary, secondary and tertiary prevention	<p>“Primary prevention is directed at the prevention of illnesses by removing the causes. The target group for primary prevention is those that are healthy with respect to the target disease.</p> <p>Secondary prevention aims at identifying the disease at an early stage so that it can be treated. The target group for secondary prevention consists of people who are already ill without being aware of it, or those who have an increased risk or a genetic disposition.</p> <p>Tertiary prevention is directed toward people who are already known to have an illness. This is therefore a form of care. Tertiary prevention includes activities intended to cure, to ameliorate or to compensate. For example, the avoidance of complications of the prevention of progress of disease would be classed as tertiary prevention.”</p> <p>(Answer to DG SANCO consultation on chronic diseases, 2012. European Union Health Policy Forum http://ec.europa.eu/health/major_chronic_diseases/docs/hpf_response_consultation_cd_en.pdf).</p>
eHealth	<p>Refers more generally to the use of electronic communication and information technology in the health sector.</p> <p><i>(World Health Organisation. http://www.who.int/topics/ehealth/en/, retrieved: 2 April 2013).</i></p>
e-Literacy	<p>Refers to having knowledge and abilities to use electronic communication and information technology in the health sector.</p> <p><i>(EPF, based on the eHealth definition).</i></p>
Health	<p>State of complete physical, mental and social well-being and not merely the absence of disease or infirmity.</p> <p><i>(Preamble to the Constitution of the World Health Organization (1948).</i></p>
Health economics	<p>Branch of <u>economics</u> concerned with issues related to efficiency, effectiveness, value and behaviour in the production and consumption of <u>health</u> and <u>health care</u>.</p> <p><i>(Wikipedia. http://en.wikipedia.org/wiki/Health_economics, retrieved: 2 April 2013).</i></p>
(Health) equity	<p>“is the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically. <i>Health inequities</i> therefore involve more than inequality with respect to health determinants, access to the resources needed to improve and maintain health or health outcomes. They also entail a failure to avoid or overcome inequalities that infringe on fairness and human rights norms.”</p> <p><i>(World Health Organisation. http://www.who.int/healthsystems/topics/equity/en/, retrieved: 2 April 2013).</i></p> <p>“Health equity is achieved when every person has the opportunity to “attain his or her full health potential” and no one is “disadvantaged from achieving this potential because of social position or other socially determined circumstances.”</p> <p><i>(Center for Disease Control and Prevention. http://www.cdc.gov/chronicdisease/healthequity/, retrieved: 2 April 2013)</i></p>
Health in All Policies (HiAP)	<p>Refers to “a policy or reform designed to secure healthier communities, by integrating public health actions with primary care and by pursuing healthy public policies across sectors.”</p> <p><i>(World Health Organization. Health Systems Strengthening – Glossary, http://www.who.int/healthsystems/Glossary_January2011.pdf, retrieved: 2 April 2013).</i></p> <p>“HiAP is an approach which emphasises the fact that health and wellbeing are largely influenced by measures that are often managed by government sectors other than health.”</p>

	<p>(Government of South Australia, http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+reform/health+in+all+policies/background+of+the+health+in+all+policies+concept, retrieved: 2 April 2013)</p>
Health inequalities	<p>Refers to “differences in health status or in the distribution of health determinants between different population groups. Some health inequalities are attributable to biological variations or free choice and others are attributable to the external environment and conditions mainly outside the control of the individuals concerned.” (World Health Organisation, http://www.who.int/hia/about/glos/en/index1.html, retrieved: 2 April 2013). See also: “Health equity”.</p>
Health literacy	<p>“has been defined as the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment.” (World Health Organisation. Health Promotion, http://www.who.int/healthpromotion/conferences/7qchp/track2/en/, retrieved: 2 April 2013). EPF working definition: “the ability to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, the healthcare system, the market place and the political arena.” (Report of EPF Spring Conference on Health Literacy, 2008).</p>
Health promotion	<p>Is defined as “the process of enabling people to increase control over their health and its determinants, and thereby improve their health. It is a core function of public health and contributes to the work of tackling communicable and non-communicable diseases and other threats to health”. (World Health Organisation, 2005, at the Bangkok Charter for Health Promotion in a Globalized World, http://www.who.int/healthpromotion/conferences/6qchp/hpr_050829_%20BCHP.pdf).</p>
Health-related quality of life:	<p>Health-related quality of life (HRQoL) is a multi-dimensional concept that includes domains related to physical, mental, emotional and social functioning. It goes beyond direct measures of population health, life expectancy and causes of death, and focuses on the impact health status has on quality of life. A related concept of HRQoL is well-being, which assesses the positive aspects of a person's life, such as positive emotions and life satisfaction. (http://www.healthypeople.gov/2020/about/history.aspx, retrieved: 5 April 2013).</p>
Holistic health	<p>Is a concept in medical practice upholding that all aspects of people's needs including psychological, physical and social should be taken into account and seen as a whole. (Wikipedia, http://en.wikipedia.org/wiki/Holistic_health, retrieved: 2 April 2013).</p>
Informal carer	<p>A carer is a person who provides unpaid care to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal framework. (Eurocarers, http://www.eurocarers.org/, retrieved 2 April 2013).</p>
Information and Communications Technology or ICT,	<p>Is often used as an extended synonym for <u>information technology</u> (IT), but is a more specific term that stresses the role of unified communications and the integration of telecommunications (<u>telephone</u> lines and wireless signals), computers as well as necessary <u>enterprise software</u>, <u>middleware</u>, storage, and audio-visual systems, which enable users to access, store, transmit, and manipulate information. (Wikipedia, http://en.wikipedia.org/wiki/Information_and_communications_technology, retrieved: 2 April 2013).</p>
Integrated care	<p>“is a concept bringing together inputs, delivery, management and organization of services related to diagnosis, treatment, care, rehabilitation and health promotion. Integration is a means to improve the services in relation to access, quality, user satisfaction and efficiency.”</p>

	<p>(WHO Europe Office cited in <i>Integrated care. A position paper of the WHO European office for integrated health care services, 2001, Oliver Gröne, Dipl. Soz., MSc, Public Health, Research Assistant, Head of the Office and Mila Garcia-Barbero, MD, PhD</i> http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1525335/?report=reader#r51)</p>
Meaningful patient involvement	<p>Patient involvement where “patients take an active role in activities or decisions that will have consequences for the patient community, because of their specific knowledge and relevant experience as patients. The involvement must be planned, appropriately resourced, carried out, and evaluated according to the values and purposes of: the participating patients or patient organisations; other participating organisations and funding bodies; and the quality of their experiences during the involvement activity.”</p> <p>(from the Value+ project, http://www.eu-patient.eu/projects/valueplus/resources/valueplus_resources.php)</p>
Medical device	<p>Refers to “any instrument, apparatus, appliance, material or other article, whether used alone or in combination, including the software necessary for its proper application intended by the manufacturer to be used for human beings for the purpose of:</p> <ul style="list-style-type: none"> - diagnosis, prevention, monitoring, treatment or alleviation of disease, - diagnosis, monitoring, treatment, alleviation of or compensation for an injury or handicap, - investigation, replacement or modification of the anatomy or of a physiological process, - control of conception, <p>and which does not achieve its principal intended action in or on the human body by pharmacological, immunological or metabolic means, but which may be assisted in its function by such means.”</p> <p>(Council Directive 93/42/EEC of 14 June 1993 concerning medical devices, EUR-LEX, http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CONSLEG:1993L0042:20071011:en:PDF, retrieved: 2 April 2013).</p>
Nanodevices / nanoparticles	<p>Refer to particles smaller than 100 nanometers (one-billionth of a meter). In medicine, nanoparticles can be used to carry antibodies, drugs, imaging agents, or other substances to certain parts of the body.</p> <p>(National Cancer Institute, http://www.cancer.gov/dictionary?expand=N, retrieved 2 April 2013).</p>
Nanotechnology	<p>Is the field of research that deals with the engineering and creation of things from materials that are less than 100 nanometers (one-billionth of a meter) in size, especially single atoms or molecules.</p> <p>(National Cancer Institute, http://www.cancer.gov/dictionary?expand=N, retrieved 2 April 2013).</p>
Patient	<p>Is any recipient of health care services. The patient is most often ill or injured and in need of treatment by a health care provider. Due to concerns such as dignity, human rights and political correctness, the term "patient" is not always used to refer to a person receiving health care. Other terms that are sometimes used include health consumer, health care consumer or client. However, such terminology may also be offensive to those receiving public health care as it implies a business relationship. Individuals who use or have used psychiatric services sometimes refer to themselves as consumers, users, or survivors.</p> <p>(Wikipedia. http://en.wikipedia.org/wiki/Patient, retrieved 2 April 2013).</p> <p>EPF refers to the term ‘patient’ to indicate people with a chronic disease. Moreover, patients are not merely receivers of healthcare services but proactive subjects and actors in the management of their disease.</p>
Patient centeredness	<p>"encompasses qualities of compassion, empathy, and responsiveness to the needs, values, and expressed preferences of the individual patient. In addition, translation and interpretation services facilitate communication between the provider and the patient and are often a legal requirement. The patient-centred approach includes</p>

	<p>viewing the patient as a unique person, rather than focusing strictly on the illness, building a therapeutic alliance based on the patient's and the provider's perspectives".</p> <p><i>(National Healthcare Disparities Report, 2010, http://www.ahrq.gov/research/findings/nhqrdr/nhdr10/Chap5.html#ref1)</i></p>
People-centred care:	<p>Refers to care that is focused and organised around the health needs and expectations of people and communities rather than on diseases. People-centred care extends the concept of patient-centred care to individuals, families, communities and society. Whereas patient-centred care is commonly understood as focusing on the individual seeking care—the patient—people-centred care encompasses these clinical encounters and also includes attention to the health of people in their communities and their crucial role in shaping health policy and health services.</p> <p><i>(World Health Organization Health Systems Strengthening – Glossary, http://www.who.int/healthsystems/Glossary_January2011.pdf).</i></p>
Patient and Public Empowerment (PPE)	<p>A multi-dimensional process that helps people gain control over their own lives and increases the capacity of people to act on issues that they themselves define as important.</p> <p><i>(Luttrell et al. (2009), Understanding and operationalising empowerment. Overseas Development Institute working paper.)</i></p> <p>A process through which individuals and social groups are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and take political, social, and cultural action to meet those needs.</p> <p><i>(Deepening our Understanding of Quality improvement in Europe; http://www.duque.eu/).</i></p> <p>See also: EPF Background Brief on Patient Empowerment: http://www.eu-patient.eu/globalassets/campaign-patient-empowerment/epf_briefing_patientempowerment_2015.pdf</p>
Patient and Public Involvement (PPI)	<p>The extent to which patients and their families or caregivers, whenever appropriate, participate in decisions related to their condition (e.g. through shared decision-making, self-management) and contribute to organisational learning through their specific experience as patients (e.g. patient reporting of adverse events or participation in root cause analysis related to their care).</p> <p>Collective patient/public involvement is the extent to which patients and citizens, through their representative organisations, contribute to shaping the health care system through involvement in health care policy-making, organisation and delivery.</p> <p><i>(European Patients Forum for PaSQ, adapted from the Value+ project: http://www.eu-patient.eu/Initatives-Policy/Projects/EPF-led-EU-Projects/ValuePlus/)</i></p>
Patients' perspective:	<p>In line with the EPF Constitution, this also embraces the perspective of the informal carers (families, partners, friends), in cases where the patient is unable to represent him or herself, or would need additional support to do that.</p>
Patient safety	<p>Patient safety as a state of being is “freedom, for a patient, from unnecessary harm or potential harm associated with health care.”</p> <p><i>(WHO patient safety curriculum for medical schools, http://www.who.int/patientsafety/activities/technical/who_mc_guide-topics.pdf)</i></p> <p>Patient safety as a discipline is the reduction of the risk or harm associated with health care to an acceptable minimum. An acceptable minimum refers to the collective notions of i) given current knowledge, ii) resources available and iii) the context in which care was delivered, weighed against the risk of non-treatment or other treatment.</p> <p><i>(Based upon the definition World Health Organization, World Alliance for Patient Safety, 2009. Conceptual Framework for the International Classification for Patient Safety Version 1.1. Final Technical Report,</i></p>

	http://www.who.int/patientsafety/implementation/taxonomy/icps_technical_report_en.pdf .
Personalised Medicine	<p>There is no commonly agreed definition of personalised medicine.</p> <p>The FDA refers to «precision medicine» as an «innovative approach to tailoring disease prevention and treatment that takes into account differences in people's genes, environments, and lifestyles. The goal of precision medicine is to target the right treatments to the right patients at the right time.»</p> <p>The EU Council Conclusions of 7 December 2015 stated that despite the lack of an agreed definition, personalised medicine it is widely understood as a medical model using characterisation of individuals' genotypes and phenotypes (e.g., molecular profiling, medical imaging, lifestyle data) for tailoring the right therapeutic strategy for the right person at the right time, and/or determining the predisposition to disease and/or delivering timely and targeted prevention.</p>
Pharmacovigilance (PhV)	<p>Is defined as the science and activities relating to the detection, assessment, understanding and prevention of adverse effects or any other drug-related problem.</p> <p>(World Health Organisation. <i>Pharmacovigilance</i>, http://www.who.int/medicines/areas/quality_safety/safety_efficacy/pharmvigi/en/, retrieved 2 April 2013)</p>
Policy	<p>Is a plan of action to guide decisions and actions. The policy process includes the identification of different alternatives, such as programmes or spending priorities, and choosing among them on the basis of the impact they will have.</p> <p>Policies can be understood as political, management, financial, and administrative mechanisms arranged to reach explicit goals.</p>
Public health	<p>Refers to all organised measures (whether public or private) to prevent disease, promote health, and prolong life among the population as a whole. Its activities aim to provide conditions in which people can be healthy and focus on entire populations, not on individual patients or diseases.</p> <p>(World Health Organisation. <i>Public Health</i>, http://www.who.int/trade/glossary/story076/en/, retrieved: 2 April 2013).</p>
Quality of life	<p>Individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.</p> <p>(Study protocol for the World Health Organization project to develop a Quality of Life assessment instrument, 1993. Retrieved from Pubmed database, http://www.ncbi.nlm.nih.gov/pubmed/8518769, on 2 April 2013).</p>
Rights-based approach	<p>In the context of EPF's work, a rights-based approach relates to access to healthcare as a basic human right, and the notion of the patient as an equal citizen.</p>
Solidarity	<p>Refers to the unity that produces or is based on community of interests, objectives, and standards.</p> <p>(Wikipedia. http://en.wikipedia.org/wiki/Solidarity#cite_note-dict1-1, retrieved 2 April 2013).</p> <p>"A degree of social solidarity is required to develop universal health coverage, given that any effective system of financial protection for the whole population relies on the readiness of the rich to subsidize the poor, and the healthy to subsidize the sick."</p> <p>(World Health Organization, 2010. <i>Report on universal coverage</i>. http://www.who.int/whr/2010/en/index.html)</p>
Under-represented patients	<p>This term is used by EPF to indicate those patients who for various reasons are not empowered to have their needs and perspective heard. The reasons for this could be the belonging to a minority group; being the object of stigma and discrimination; being in a vulnerable position due to social and economic factors.</p> <p>As a result the needs of these patients are insufficiently represented or not represented at all in decision- and policy-making structures and processes.</p>

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