

Toolkit for Patient Organisations on Patient Empowerment

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1 Introduction

Patient empowerment is at the root of EPF's vision and mission, and one of our Strategic Goals included in the Strategic Plan 2014-2020:

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.

EPF conducted a one-year dramatic campaign on patient empowerment in 2015-2016, in order to promote understanding of what patient empowerment means *from the patient perspective* among political decision-makers and health stakeholders. As part of the campaign deliverables, we developed a Patient's Charter on Patient Empowerment and a Roadmap for Action. (See "Campaign resources", below.)

1.1 WHY PATIENT EMPOWERMENT IS NEEDED

Chronic diseases are seen as a sustainability challenge for European health systems. This is usually presented in terms of funding – our health systems cannot cope financially with chronic conditions and the ageing population.

But from a patient's perspective, the health systems are often unable to cope well with chronic conditions *because they do not meet patients' needs*.¹²

Financing of the health system plays a role (e.g. chronic underfunding, lack of adequate numbers of healthcare professionals...), but often the system challenge has more to do with the way healthcare is delivered and services organised: fragmentation of care is a major problem for patients, who often have to "fight the system" just to get the care they need.

Chronic disease requires a fundamental shift from disease-centred to patient- and family-centred approach, combining self-management in the community with well-integrated professional support through the life-course. Patients are *experts by lived experience*, whose perspective on disease and care is unique. This implies the empowerment of patients and their involvement at every level in the health system, ensuring active patient involvement in policy-making and in co-designing of care services to meet their needs more effectively.

Some of the reasons why patient participation is still absent in some key health areas, and not strong enough in others include lack of awareness and recognition of patient empowerment; slow pace in sharing and adopting good practices; lack of resources in the health system but also of patient

¹ See for example [EPF paper on chronic diseases](#) (2012) and [healthy and active ageing](#) (2011).

² "Patients" is used in this paper for brevity, but it should be taken to include the whole family. Also, although EPF as an organisation represents patients with chronic conditions, the same principles of empowerment can apply to any healthcare user who is, even if temporarily, in a situation of being a "patient".

organisations; poor know-how on how to meaningfully involve patients and patient organisations; and a patient community with very different levels of capacity and different priorities across the EU.

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.³

1.2 IS “PATIENT EMPOWERMENT” UNDERSTOOD AND USED BY ALL ACTORS TOWARDS THE SAME GOALS?

Patient empowerment is a popular “buzzword” in health policy. It has been recognised as a priority in the European Union Member States’ parallel “reflection processes” focusing on chronic diseases and health systems sustainability⁴; however, patient empowerment in EU discourse is often perceived primarily in very limited terms: often as **self-management**. Not surprisingly, the most developed and researched areas in terms of interventions towards patient empowerment are in the area of self-management.

Another concept often underlying talk about patient empowerment is that of a “**consumer choice**”, which effectively reduces empowerment to the ability to choose a healthcare provider based on information that enables a patient to compare different options.⁵ The discourse of patient-centricity is sometimes employed as a way of legitimating actions that are not truly patient-centred. **Tokenism** remains an issue; this is very apparent when it comes to patients’ participation in medical conferences, and possibly even more when it comes to health policy conferences that concern the patient community.⁶

1.3 HOW TO USE THIS TOOLKIT

Notes: all the illustrations in this document are taken from EPF’s materials and are available through links in the “Resources” section, e.g. in PowerPoint format.

EPF materials available on our website are free to use as long as an appropriate reference is made to the source. We would appreciate it if external stakeholders (i.e., not EPF member organisations) let us know when they are intending to use our materials. Please see contact details at the end.

³ 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.

⁴ https://ec.europa.eu/health/sites/health/files/major_chronic_diseases/docs/reflection_process_cd_final_report_en.pdf

⁵ See report from EPF’s conference on empowerment (2015), pp. 18-20. <http://www.eu-patient.eu/globalassets/campaign-patient-empowerment/pe-conference-report.pdf>; “Patients’ Rights in the European Union. Mapping exercise. Final report, 2016. https://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2018_mapping_patientsrights_frep_en.pdf

⁶ See for example <https://patientsincluded.org>.

2 Definitions

This section deals clarifies the definitions of patient empowerment and related concepts.

Why such a lengthy section on terminology?

When advocating about empowerment it is recommended to clarify the terms in the beginning so that everyone ‘speaks the same language’. To quote a recent publication, “different terms stress different issues and suggest different kinds of questions. For example, ‘collaborative care’ does not present the clinician as the key support for the main actor in the more obvious way that ‘support for self-management’ does. It also does not imply that ‘health’ is the main or only goal of care in the way that ‘co-creating health’ does. The particular connotations of any of these terms can vary across audiences ... Although they are in some senses only words or labels [terms] influence how clinicians and patients think about and experience their interactions with each other, as well as issues in the management of long-term conditions.”⁷

The difficulty with defining *patient empowerment* in a way that is understandable to everyone is that it is essentially a rather abstract, intangible concept. It is also not easy to distinguish clearly between patient empowerment and patient involvement. In certain contexts such as research, the term *patient engagement* is also often used. EPF uses the following definition of empowerment, originally developed for the EU Joint Action on Patient Safety and Quality of Care (PaSQ):

Empowerment is “a multi-dimensional process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important.” Collective empowerment is “a process through which individuals and communities 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.”⁸

The EMPATHIE conceptual framework

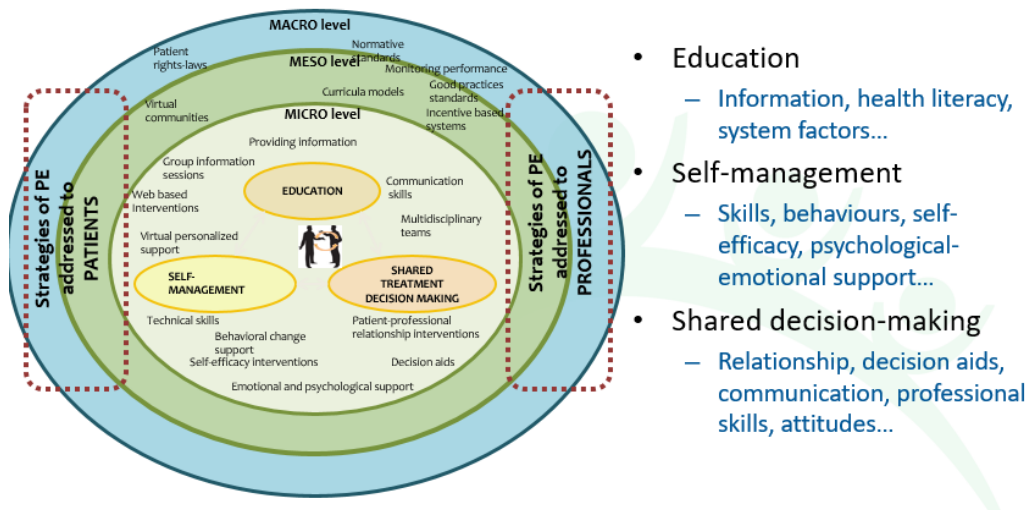
The EMPATHIE study in 2014 (“Empowering Patients in the Management of Chronic Diseases”), in which EPF was a partner, was the first European Commission-funded mapping study of patient empowerment. EMPATHIE identified three key areas of empowerment: information/education (health literacy); shared decision-making; and self-management. These areas are mutually reinforcing, complementary and to some extent overlapping. Aspects of empowerment also include self-efficacy, self-awareness, confidence and coping skills.^{9,10}

⁷ Entwistle and Cribb (2013) Enabling people to live well, The Health Foundation. pp. 9-10. Available online at <http://www.health.org.uk/publication/enabling-people-live-well>

⁸ PaSQ, adapted from Luttrell et al. 2009 and the Duque project (www.duque.eu)

⁹ The final summary report of EMPATHIE is available at http://ec.europa.eu/health/patient_safety/docs/empathie_frep_en.pdf.

¹⁰ Health literacy refers to the (cognitive and social) skills of people that determine their ability and motivation to access and understand health-related information, judge its quality or trustworthiness, and to take appropriate action – e.g., regarding lifestyle choices, self-care and so on. For more information, see "Health Literacy. The Solid Facts" (WHO, 2013) available at http://www.euro.who.int/_data/assets/pdf_file/0008/190655/e96854.pdf



- Education
 - Information, health literacy, system factors...
- Self-management
 - Skills, behaviours, self-efficacy, psychological-emotional support...
- Shared decision-making
 - Relationship, decision aids, communication, professional skills, attitudes...

The EMPATHIE study developed the following working definition of *an empowered patient*. This definition in fact **combines both empowerment and involvement**: to show this we have highlighted in green words related to empowerment, and in purple words related to involvement:

“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.”¹¹

The **main drawback of this definition** is that it focuses only on the individual patient and its scope is limited to managing life with a chronic condition, even though it does go beyond the purely medical context. It does not include the notion of “critical awareness” and patients’ active participation with the aim of changing the system.¹² It also does not address the role of patient organisations as representatives of the patient community in a wider sense whose role is to advocate for the patient perspective at policy level. Nevertheless, it can be a useful reference point as it is backed up by an EU funded study and a conceptual framework.

Empowerment can be seen as a *philosophy, vision or goal* as well as a *strategy or process*. We can think of empowerment as a **relational concept**: on the one hand, an internal process whereby individual people increase their capacity to live well with chronic conditions in their daily life, as well as act within the healthcare, social, work and other environments. On the other hand, it is fundamentally a **systems issue**: the processes and structures people come into contact with – for example, but not exclusively, in the healthcare environment – can be empowering or disempowering.

¹¹ EMPATHIE Summary Report, 30 September 2014 available at http://ec.europa.eu/health/patient_safety/docs/empathie_frep_en.pdf

¹² “Self-Management: A Background Paper”. Patrick McGowan, PhD, University of Victoria – Centre on Aging. 2005, p. 3

At micro level (the individual patient), the healthcare professional is the most important contact point for the patient and the system; (dis)empowerment often manifests in the patient-professional relationship. At meso level (organisation, e.g. hospital), the care delivery processes or the design of the environment can be (dis)empowering. At macro level (policy), factors that contribute to (dis)empowerment can include information to patients or the lack of it, implementation of patients' rights laws, (lack of) opportunities for patients to participate in health policy, (lack of) transparency of the system, and lack of access to healthcare.

Patient empowerment is:

- A process (not static)
- Non-binary (there are degrees of empowerment)
- Non-linear (going 'back' as well as 'forward')
- Context-dependent
- Something that cannot be imposed by others, but can be facilitated
- Both individual (patient) and collective (the patient community).

2.1 RELATED CONCEPTS

This section gives definitions of concepts closely related to, complementary to and sometimes used by healthcare stakeholders instead of patient empowerment.

Meaningful patient involvement

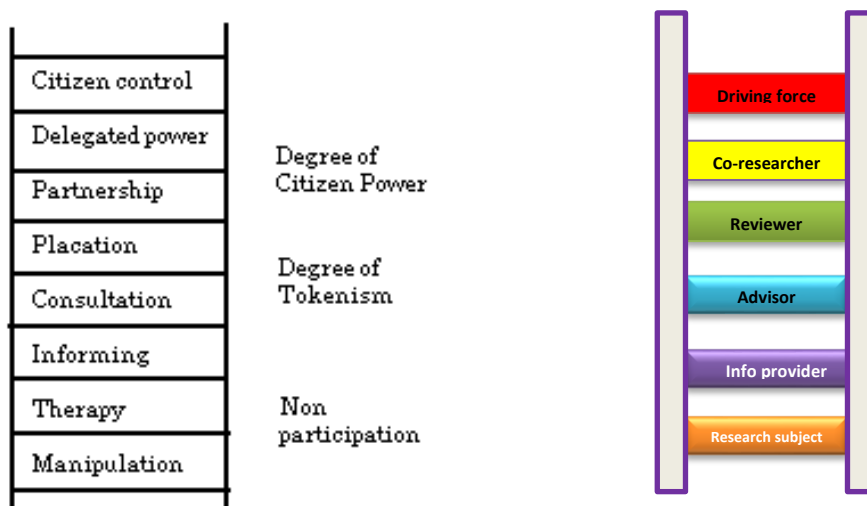
Patient empowerment and involvement are closely related. Involvement (or participation) has both an individual and a collective dimension and both can take place at micro, meso and macro levels. For example, at individual (micro) level, patients participate as partners in the care process through shared decision-making and self-management. At organisation (meso) level, patients can be involved in quality improvement initiatives at hospitals. At policy (macro) level, patient organisations participate in shaping health policy.

Meaningful patient involvement as defined by EPF¹³ is based on the premise that patients have a *specific expertise* derived from simply being patients, which is a valuable source of *experiential knowledge*. The patient perspective is thus not the same as the general public, lay or consumer perspective. The patient's knowledge is derived from living with a condition day-to-day and from being in frequent contact with the healthcare system. Individual patient involvement refers to "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

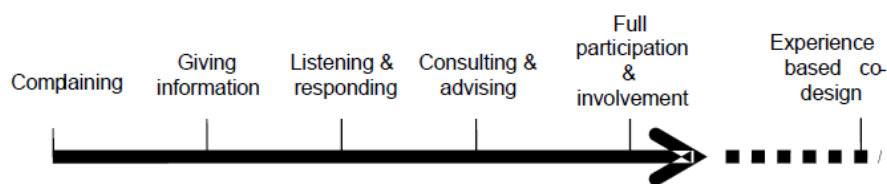
¹³ "Patients take an active role in activities or decisions that will have consequences for the patient community, because of their *specific knowledge and relevant experience as patients*. The involvement must be planned, appropriately resourced, carried out, and evaluated as to its outcomes, impact and the process itself, according to the values and purposes of all participants." (EPF project "VALUE+", 2009).

organisational learning through their specific experience as patients”.¹⁴ Collective patient involvement is “the extent to which patients, through their representative organisations, contribute to shaping the health care system through involvement in health care policy-making, organisation, design and delivery”.¹⁵ Interestingly, a 2012 Eurobarometer survey on Patient involvement found that patients with chronic disease tend to be more knowledgeable and motivated to be involved in their care – and are also more critical of health system – than other people.

An international reference point for patient involvement is the Alma Ata declaration (1978), which defined civic involvement in healthcare as both a right and a duty: “The people have *the right and duty to participate* individually *and collectively* in the planning and implementation of their healthcare.”¹⁶ Levels of meaningful involvement are often illustrated by the “ladder” model, first developed by Sherry Arnstein in 1969¹⁷ (left). This model has been variously adapted, including for patient involvement in research by the PatientPartner project¹⁸ (right).



The illustration below from Bate and Robert (2006)¹⁹ shows how patient involvement, specifically in healthcare, can evolve from rather passive “involvement” to active partnership:



¹⁴ Adapted from the EPF Value+ project

¹⁵ Co-developed by EPF for the PaSQ Joint Action

¹⁶ Alma Ata Declaration, Principle IV. 1978, WHO.

¹⁷ Arnstein, Sherry R. "A Ladder of Citizen Participation," *JAIP*, Vol. 35, No. 4, July 1969, pp. 216-224. Accessed at <http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html>

¹⁸ PatientPartner (2010) project funded under EU FP7. www.patientpartner-europe.eu

¹⁹ “Experience-based design: from redesigning the system around the patient to co-designing services with the patient” Bate P and Robert G, *Qual. Saf. Health Care* 2006; 15; 307-310.

In addition to being a patient's right, patient involvement is recognised as having benefits for developing therapies and healthcare services in a way that benefits patients and society.²⁰

Health literacy

Health literacy is a key aspect of empowerment (EMPATHIE framework). Although empowerment involves much more than becoming an educated/informed patient, the right information and resources are fundamental tools for empowerment. Health literacy, however, is more than information. It is "linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in every-day life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course."²¹

Well-informed, health literate people are more discerning about their health, in a position to make more informed choices and decisions, and more likely to seek earlier diagnosis and recover faster. The converse is also true.²² From a patient's perspective, the knowledge and competence gained through health literacy leads to the strength and empowerment needed to manage well a disease and its impacts on quality of life.

Health literacy starts with *good, easily understandable information*: information is not enough in itself but a tool towards improved health literacy. Targeted health literacy interventions are often necessary, and they can be particularly useful to reach out to specific vulnerable groups, such as the young and the old, persons with mental illness and their families, and minority/migrant or socio-economically marginalised groups.

Self-management

Self-management is a key element of empowerment (EMPATHIE framework) and of patient-centred care: in chronic conditions, the management of the condition is mostly handled by the patient at home and in the community, so in this sense patients already "self-manage". Self-management can be understood as a partnership between patients and the healthcare team: the team should support patients in "living with" their illness and in managing the conditions and their physical, psychological, emotional and social impacts. Through self-management support, patients can develop the confidence, self-efficacy and skills to be in control of their daily life and attain the greatest possible quality of life and health outcomes. Self-management, therefore, does not mean leaving the patient to cope on their own. It is a holistic approach providing the appropriate support and tools according to each person's individual needs and preferences. There are a number of theoretical models on self-management, including Bandura's self-efficacy theory. **Self-efficacy** "pertains to an individual's belief in their capacity to successfully learn and perform a specific behaviour. A strong sense of self-efficacy leads to a feeling of control and to the willingness to take on (and persist with) new and difficult tasks. When applied to health, this theory suggests that patients are empowered and motivated to manage

²⁰ On research see Levitan et al. (2017), "Assessing the Financial Value of Patient Engagement. A Quantitative Approach from CTTI's Patient Groups and Clinical Trials Project", *Therapeutic Innovation & Regulatory Science*, 1-10.

²¹ Kickbusch et al. (eds.) Health literacy. The solid facts. World Health Organization. http://www.euro.who.int/data/assets/pdf_file/0008/190655/e96854.pdf

²² "Health Literacy – part 2: evidence and case studies", World Health Communication Associates, 2010, pp. 20-22. Available online at www.whcaonline.org/uploads/publications/WHCAhealthLiteracy-28.3.2010.pdf

their health problems when they feel confident about their ability to achieve their goal. Interventions for improving self-care should therefore focus on building confidence and equipping patients with the tools (knowledge and skills) to set personal goals and develop effective strategies for achieving them.”²³

Shared decision-making

At the heart of the empowerment approach is seeing the patient-professional relationship as a partnership of equals. Empowerment does not happen in a vacuum: it is a two-way process. The patient needs a counterpart in the “empowered health professional” who welcomes the patient’s involvement and knows how to create an enabling healthcare environment.

All health professionals need to develop the *necessary skills and attitudes* to adapt to the new patient role, shifting *from a paternalistic medical model to a collaborative model*. Key barriers identified in the EMPATHIE study included lack of time/shortages of staff, and patients’ lack of information – but attitudes of health professionals were seen as most important barriers by *all* stakeholders.

A number of tools exist also for patients, such as *decision-aids* intended to help patients weigh the benefits and potential harms of different treatment options. A recent Cochrane review found that when patients use decision aids they: improve their knowledge of treatment options, feel more informed and clear about what matters most to them, have more accurate expectations of benefits and harms, and participate more in decision-making. Patients also tend to choose less interventionist approaches to treatment.²⁴ In accordance with this finding, a recent study in Denmark found that 40% fewer patients opted for surgery (hip/knee replacement) after engaging in a shared decision-process with a video explaining all the options.²⁵

Patient -centred healthcare

Patient-centredness is recognised as an element of the quality of healthcare, though in a recent overview of definitions of quality it was less frequently mentioned than effectiveness, efficiency, access, equity, safety and appropriateness.²⁶ There is no common agreed definition of patient-centred care, or what its components are.²⁷ Existing definitions use varying terminology and have different nuances (it is sometimes referred to as “responsiveness” or “satisfaction”).²⁸ Nevertheless literature is accumulating, including guidelines for implementation and measurement of patient-centredness.

Most definitions see patient-centredness as *a system of care organised around the patient*. Some definitions refer to *person-centred healthcare*, possibly out of a reluctance to define all people

²³ Coulter A, Parsons S, Askham J (2008) “Where are the patients in decision-making about their own care?” Policy brief, WHO for the European Observatory on Health Systems and Policies ; Ory M, Lorig K, et al, (2013). Medical Care, November 2013. P. 13.

²⁴ Stacey et al. (2014) “Decision aids for people facing health treatment or screening decisions” Cochrane review. <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD001431.pub4/abstract>

²⁵ <http://patientsikkerhed.dk/in-english/publications.aspx>

²⁶ “Future EU agenda on quality of health care with a special emphasis on patient safety”, EXPH final opinion adopted to 9 October 2014, p.23. Available at <https://publications.europa.eu/en/publication-detail/-/publication/b11c6d01-0723-4c9b-a6ba-dcfd787109d3>

²⁷ De Silva (2014) *Helping Measure Person-Centred Care*. The Health Foundation. <http://www.health.org.uk/publication/helping-measure-person-centred-care>

²⁸ However, these concepts are not exactly the same.

seeking/using healthcare as patients²⁹ but in their essential elements these definitions are very similar to patient-centred healthcare. Many definitions focus on patients' participation in their own care (NIH) and individual patients' preferences, such as this well-known one:

“Providing care that is respectful of and responsive to individual patient preferences, need, and values, and ensuring that patient values guide all clinical decisions” (*Institute of Medicine, 2001*)

Rather than adopting a certain definition EPF uses as our reference point the **six principles of patient-centred healthcare**, developed by IAPO in 2005.³⁰

Principles of patient-centred healthcare:

1. Respect for patients' unique needs, preferences, autonomy
2. Choice of appropriate treatment option that best fits patients' needs
3. Patient empowerment and involvement in decisions that concern their health
4. Access to safe, high-quality, appropriate services and support
5. Information that is reliable, relevant and understandable
6. Patient involvement in health policy to ensure services are designed with the patient at the centre

(International Alliance of Patients' Organizations – IAPO, 2005)

These principles contain many fundamental aspects of patient-centredness although they do not explicitly include for example integration/continuation of care,³¹ self-management support, or meaningful patient feedback as a learning and improvement resource. Health literacy is implicit but not spelt out. Principles 2 and 3 are somewhat overlapping and the concept of “choice” could be more clearly differentiated from consumer choice or patient satisfaction. The principles are rather abstract, and they need to be operationalised into practices in order to assess to what extent they have been achieved at different levels of the healthcare system and/or stages in the patient's “journey”.

It is worth quoting the recent European Commission's Expert Panel opinion paper at length: “[patient-centredness] is not only a question of patients' ‘desires’ been taken into account. Nor only a question to ‘responding’ to the needs and preferences of patients. These are necessary but not enough. Patients, families and people, should have the possibility to actively participate in the process of care and self-care, particularly for chronic conditions, health promotion, disease prevention, and patient safety activities. ... So, the services have not only to be developed ‘for’ individuals and populations, but also ‘with’ and ‘through’ individuals and populations. It is not only a question of ‘expectations’, but also of empowering and increasing the capacity of individuals/patients to be able to care for themselves in partnership with professionals (e.g. in relation to diabetes, mental disorders, ageing with autonomy, etc.) and to achieve the ‘goals’ in their lives that are relevant to them.” The EXPH

²⁹ Others still encompass the whole community, rather than only individuals (e.g. *People at the Centre of Health Care: Harmonizing mind and body, people and systems*. World Health Organization, Western Pacific Region, 2007).

³⁰ link

³¹ Fragmentation – between levels of care and between health and social care – is identified by patients with chronic diseases as a major obstacle in the way of good quality care. (EPF, 2011)

description is in line with EPF’s principle of meaningful patient involvement; it also cautions against inappropriate shifting of responsibility to patients, or replacing high-quality health services with technology.

Integrated care

Integrated care is a popular concept in health systems re-design. From the patient perspective, it means care that is well co-ordinated so it meets the needs of patients (and their families) in a holistic way. We could say that “integrated care” is a systems/organisational concept whereas patients like to refer to “continuity” or “co-ordination” of care, with smooth transitions between different settings, and services that are responsive to all their needs in totality. EPF’s member organisation National Voices has developed a set of Principles of integrated care, which describe what successfully integrated care looks like for a patient and family.³²

2.2 IMPORTANT CAVEATS – WHAT PATIENT EMPOWERMENT IS NOT

What if patients do not want to be empowered?

It is important to recognise that empowerment cannot be imposed “top down” - although it can be facilitated. A patient may choose not to participate in decision-making, delegating this to health professionals. The same patient, in different circumstances, may wish to be more or less involved in the decision. Equally, a patient may opt not to receive any treatment, after a discussion of all the options. Some patients may want to leave treatment decisions to the professional. Patients in acute situations, for example emergency hospitalisation, are less likely to be (able to be) actively involved than patients managing a chronic condition at home, simply due to the circumstances. There are also some cultural differences in perceptions of patient involvement.³³ Nevertheless, the EPF Charter states that no-one should be considered “beyond” empowerment – some people may just need more support than others.

Does empowerment mean shifting the responsibility on to the patient?

The empowerment approach aims to realise the vision of patients as “co-producers” of health and as integral actors in the health system. Many patients would like to take more responsibility for their own health and care, given the opportunities and support to do so. To achieve this, there is a need to support patients, inter-alia through high-quality information and health literacy, but also to equip health professionals with the necessary skills to work in partnership with patients. There should be no question of shifting responsibility *inappropriately* on the shoulders of patients (for example regarding patient safety, where patients can certainly contribute but should not be held responsible for ensuring their own safety).

Is empowerment about making patients into consumers?

Patient empowerment in EPF’s view is not about reducing healthcare to a transaction or a consumer good. It is not about consumerisation of healthcare, and it is not about blaming individual patients for consuming a lot of healthcare resources, or using a lot of services, because they are ill.

³² <https://www.nationalvoices.org.uk/publications/our-publications/principles-integrated-care>

³³ Coulter A, Parsons S and Askham J (2008) “Where are the patients in decision-making about their own care?” WHO Policy brief, pp. 3-4.

What about access?

Equity of access and patient empowerment are closely interlinked. At the same time, there are real risks that empowerment approaches, if not carefully implemented, may exacerbate existing inequalities. Some groups and individuals may be more in need of empowerment than others, and “one size” is not likely to fit all needs. EPF’s position is that equity and empowerment are both system issues: Health systems and services should be designed to be empowering for all users, including disadvantaged or socially excluded patients. Application of patients’ rights and human rights generally should be ensured, such as meaningful informed consent focusing on the patient’s ability to make meaningful choice, rather than on legal protection of healthcare staff; effective mechanisms should be in place to ensure non-discrimination, both within the health system and outside the health system.³⁴

³⁴ See EPF's work on [non-discrimination](#).

3 EPF’s Key Advocacy Tools on Patient Empowerment

The EPF thematic campaign in 2015-2016 used the tagline “Patients prescribe E5 for sustainable health systems” to demonstrate that patients are active people who can, if supported and according to their individual capabilities and situation, make a difference for the sustainability of healthcare systems.

The five “E”s of empowerment stand for:

1. **Education** We can make informed decisions about our health if we have the appropriate education and information tools;
2. **Expertise** We self-manage our condition every day, so we have a unique expertise and experience to contribute to the design and reform of health systems;
3. **Equality** We can make decisions about our health in equal partnership with health professionals;
4. **Experience** We are part of patients’ organisations that represent us and channel our experience and our collective voice;
5. **Engagement** We need to be engaged in co-designing more effective services and in research into new treatments – but we also need the engagement of wider society.

Suggestions for use

The five “E”s have a linguistic limitation: they only work in English, but we nevertheless encourage their adaptation into different languages where possible, and the key messages remain relevant. The visual (right), which does not rely on the five “E”s, can be used in many contexts to illustrate the potential of patient empowerment.

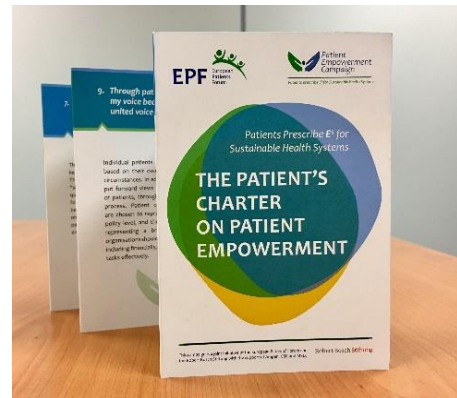
The EPF campaign produced a number of other resources, including slide sets and videos with patient testimonials – see “Resources” section, below. Its main outcome was two important tools that can be used by all patient organisations to advocate for patient empowerment in their different contexts: the **Patient’s Charter on Patient Empowerment**, and a **Roadmap for Action**.



3.1 THE PATIENT’S CHARTER ON PATIENT EMPOWERMENT

This Charter was developed by EPF our members and it encapsulates the fundamental principles of patient empowerment as perceived by patients. The Charter can be used as an advocacy tool to promote action and culture change, whether “on the ground” or at policy level.

The Charter is a list of principles. It is not a list of patients’ rights, although it relates closely to rights. A right is only meaningful if a person is able to exercise it in practice. Empowering practices (and elimination of disempowering ones) are therefore needed in order to turn theoretical rights into a reality that patients can “live” in all their interactions with health professionals, healthcare organisations and the wider system.



Suggestions for use

The Charter is available in a poster format that can be printed and displayed anywhere – in a doctor’s surgery, at a hospital, a patient organisation’s office, or behind a policymaker’s desk... At the moment the Charter is available for downloading from EPF’s website in English, Dutch, French, Greek, Italian, Lithuanian, Romanian, Slovakian Spanish (see “Resources” section).

A small “pocket” version is available in English (picture above), which can be given to policymakers, healthcare professionals or other interested persons. Please contact the EPF office if you would like to have copies.

3.2 THE ROADMAP FOR ACTION

The Roadmap for Action transforms the principles of the Charter into eighth priority action areas for driving change. For each area, it calls for a number of actions. The areas and actions are highly complementary and point towards multiple paths towards the goal of achieving health systems in Europe that are high-quality, patient centred, participatory and sustainable. The Roadmap is available in English.

No single approach on its own will address all aspects of empowerment in all different contexts, as empowerment is complex and influenced by many factors. In many cases there is a need for further research to understand the state-of-the-art and identify gaps. In some cases, there is an established EU framework for a given policy area. In other cases, there is not.

The 8 priority areas for action

1. Health literacy & information
2. Professional training & skills
3. Self-management support
4. Patient-driven technology solutions
5. Patient involvement in patient safety
6. Patient centredness in healthcare
7. Patient involvement across the R&D lifecycle
8. Patient involvement in health policy

The Roadmap does not cover all possible actions, and we did not want to make it simply a list of “policy dossiers”. The Roadmap also does not give specific instructions on “who” should take which action:

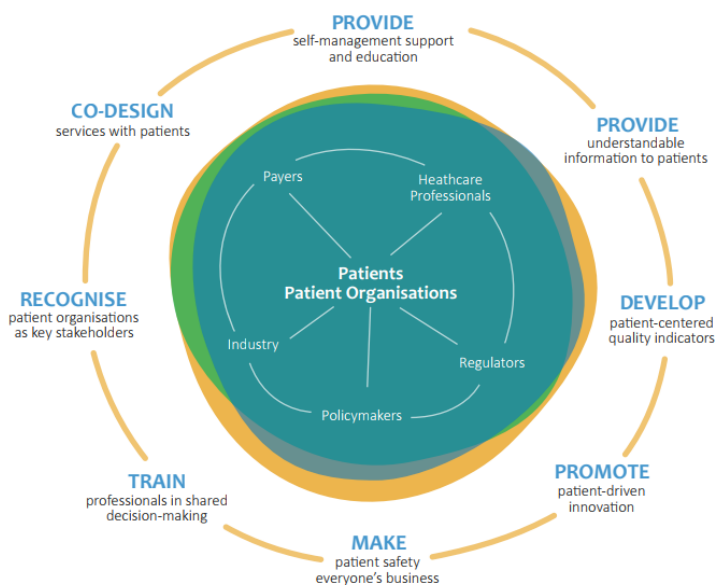
this is because we believe that real change needs the engagement of a wide range of stakeholders – patients, policymakers, different health/social care professionals, and sometimes commercial actors. It is intended to provide direction and inspiration.

Suggestions for use

To drive real changes towards patient empowerment and patient centred healthcare systems we need the support of policymakers and practitioners, not only in Brussels but everywhere across the EU countries.

Patient organisations are free to use the Roadmap as an advocacy tool and pick specific priorities from amongst its recommendations, which fit with the most urgent issues for a specific patient community or country context.

As an example, EPF at European level has started implementing Priority area 5, “Patient involvement in patient safety” by organising a conference on the empowerment of patients and families and patient safety (November 2016) and a task force in 2017, which developed a proposal on “core competencies” – knowledge, skills and attitudes – enhance patient empowerment in the area of safety.

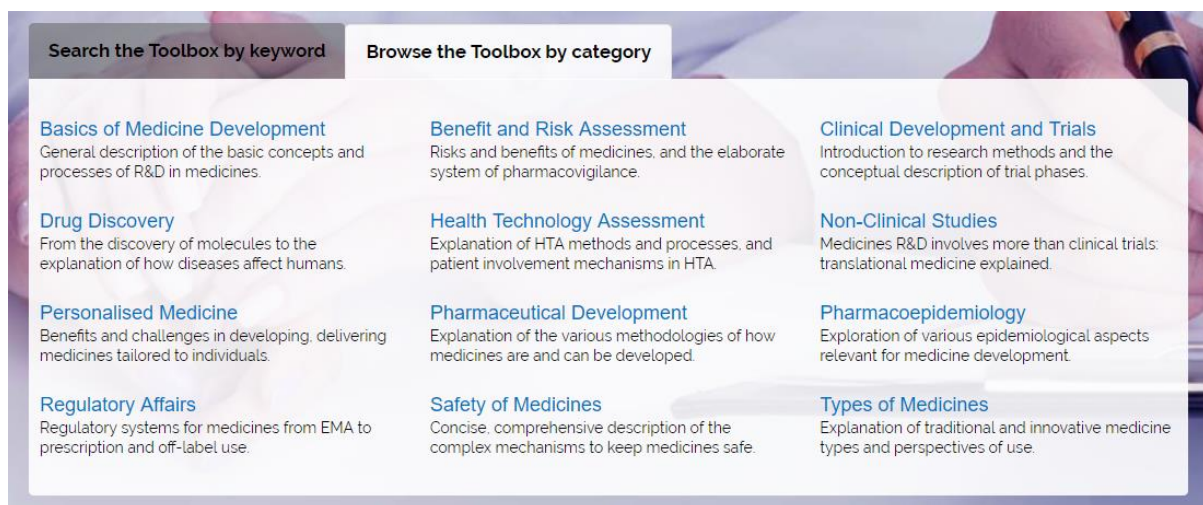


3.3 EUPATI – THE PATIENT EDUCATION RESOURCE FOR R&D

Involving patients in research can hugely benefit the medicines development process by bringing in their priorities and perspectives. Armed with a deeper understanding, patient experts and advocates will be empowered to work effectively with the relevant authorities, healthcare professionals and industry to influence the medicines development process for the benefit of patients.

The European Patients’ Academy on Therapeutic Innovation (EUPATI) was a patient education and empowerment project funded under of the Innovative Medicines Initiative³⁵ between 2012 and 2017. Its aims were to develop and disseminate accessible, understandable, scientifically reliable and user-friendly educational material for patients on medicines research and development; increase the capacity of patients to be effective advocates and advisors in research; and to empower patients to provide patient-relevant advice and insight to industry, academia, authorities and ethics committees.

The project addressed two levels: the ‘expert level’ through two **Patient Expert Training Courses** in English to patient ambassadors and patient journalists; and the ‘education level’ through the development of the **EUPATI Toolbox on Medicines R&D**. The latter is suitable for patient advocates, patients and the health-interested lay public and is available in 7 languages (English, German, Spanish, Polish, French, Russian and Italian).



In addition, **EUPATI National Platforms** have been set up in 18 countries: Austria, Belgium, Denmark, France, Germany, Greece, Ireland, Italy, Luxembourg, Malta, Norway, Poland, Portugal, Romania, Slovakia, Spain, Switzerland and UK. Additional National Platforms are currently in different stages of creation in Serbia and The Netherlands.³⁶ These National Platforms organise a variety of activities, including webinars, information days, mini trainings, and social media campaigns.

EUPATI has also published **guidance on patient involvement** in various aspects of medicines research and development.³⁷ A number of **webinars** are also available for those interested in patient

³⁵ IMI is a public-private partnership between the EU and the European Federation of Pharmaceutical Industries and Associations (EFPIA), launched in 2008. It funds projects to tackle important challenges in medical research and drug development.

³⁶ As of January 2018. The list of the National platforms is available at <https://www.eupati.eu/#eupcrib>

³⁷ <https://www.eupati.eu/guidance-patient-involvement/>

involvement, for example in ethics review of clinical trials, health technology assessment, regulation, working with industry.³⁸

Suggestions for use

The Toolbox and other resources are free for patient advocates to use. If there is no national platform in your country, and you would like to have support in setting one up, please contact the EUPATI coordinator at EPF.

3.4 VALUE+: EVALUATING THE QUALITY OF PATIENT INVOLVEMENT

Value+ (Promoting Patients' Involvement in EU Supported Health-Related Projects, 2008-9) was the first project for which EPF was awarded a grant as project leader under the European Commission's Public Health Programme. The basic premise was and is that patients' meaningful involvement leads to better results and contributes more effectively to policy towards patient-centred, equitable healthcare.

The project produced a set of tools which, although now a decade old and to some extent outdated, still contain relevant resources, especially with regards to structuring and evaluating *meaningful* patient involvement (a term coined by this project!). The Toolkit for patient organisations provides information on how they can be involved as equal partners, principles around consultation, and how to use and disseminate project outcomes efficiently. The Value+ Handbook for project leaders provides specific guidance on how to work with patient organisations.

One part of the Handbook focuses on **evaluating patient involvement**. According to the principle of meaningful patient involvement, it must be planned, appropriately resourced, carried out, and evaluated according to the values and purposes of the participating patient organisations as well as other partners; the evaluation should include the *experience of involvement* during the activity.

Suggestions for use

The Annex to the Handbook (p. 57) contains a useful evaluation grid for assessing different aspects of a project in the following domains:

- Patient involvement at the beginning and throughout the project in planning and decision-making;
- Co-operative working between patient organisations and other partners supported by a clear understanding of each other's roles;

ANNEX 4 - VALUE+ TOOLS

VALUE+ INDICATORS FOR MEANINGFUL PATIENT INVOLVEMENT

Involvement in planning and decision making

1. Patients/Patient organisations helped to identify the topic addressed by the project
2. Patients/patient organisations helped to shape the project design
3. Meaningful patient involvement and its monitoring and evaluation during the project were part of the project design
4. The patients/patient organisations involved represented the type of patients who would be affected by the project outcomes.

³⁸ <https://www.eupati.eu/category/webinar/>

- Providing information and support for involvement, including clear communication about the project itself;
- Monitoring and evaluation of patient involvement from the perspective of all the partners;
- Evaluation of the project’s results and impact, identifying how patient involvement has enhanced the results.

It also lays out the advantages and disadvantages of consultative, participatory and patient -controlled approaches. This can be very useful in communicating the principles of good practice in patient involvement to different stakeholders.

3.5 THE ‘ADDED VALUE’ OF PATIENT ORGANISATIONS

In 2017 EPF commissioned a report setting out the added value brought by patient organisations and public health and healthcare.

The report gives an overview of the role of patient organisations in Europe, highlights their value as legitimate stakeholders in civil dialogue in health-related policies and draws attention to the challenges patient organisations are facing. It stresses the contribution of patient organisations in representing and voicing the situation of specific patient populations that would otherwise not be represented. The main activities of patient organisations are set out in four different areas: policy, capacity-building and education, peer support, and research & development (in pharmaceuticals and healthcare generally).



The report makes a number of recommendations for different stakeholders, focusing in particular on European and national decision-makers and academic researchers, in areas such as systematic involvement, management of (conflicts of) interest, and evaluation of impact.

Suggestions for use

This report can be used to develop well-founded advocacy for the involvement of patient organisations in health policy and practice European, at national/regional or local levels.

4 What can patient organisations do?

EPF member organisations advocate for patient empowerment at national or EU levels. They are the driving force of patient empowerment across the EU, supporting the delivery of key messages to all EU stakeholders, decision-makers and practitioners, and raising awareness about patient empowerment in their own disease-areas or national/local contexts.

We recognise that our members have unique needs and different priorities when it comes to patient empowerment. Below are some concrete ideas for advocacy, from the very simple to the more complex, building on the suggestions made during the EPF campaign in 2015-2016. See also the suggestions for use of **the Empowerment Charter and Roadmap**, above.

Disseminate the EPF Charter, Roadmap for Action, and the patient empowerment infographic

You can disseminate these tools at your events and send them to your contacts, if you have not done so already. You can also send them via social media, traditional media and to your national decision-makers. If you cannot find the Charter in your language, we would welcome any volunteer help in translating it into further languages.

If you are invited to speak at a conference, feel free to use EPF materials to insert some content on patient empowerment! See the *standard slide sets* available on our website (in PDF); members can contact the EPF Secretariat for an editable version. Please do acknowledge the source when using our materials.

Write a blog for EPF

Share your story – whether from an individual perspective, perhaps about the importance of self-management or shared decision-making, or a collective perspective of a patient organisation.

(Are you a healthcare professional who welcomes working with empowered, involved patients? We would like to interview you!)

Share information on patient empowerment!

Although the EPF campaign has concluded, patient empowerment is at the heart of all our work and we are moving to the next level in our own advocacy at European level. We are aware that many of our members are active in their own contexts, and we would love to hear from you! Here are some ideas you can share.

Promote your good practice (or someone else's!)

Real-life situations that foster patient empowerment play an important role to demonstrate that patients add value and make a difference. EPF is collecting case studies of “good practices” – activities that promote patient empowerment at different levels in a genuine, non-tokenistic way. This way, we can gather and share with our membership more and more evidence on good ideas that are already being realised in different parts of Europe, in disease-areas, led by different stakeholders.

What are the interesting developments happening in your country or in your disease-area in patient empowerment? Tell us about challenges and roadblocks, but also successes and potential openings towards greater patient empowerment and involvement, in any area of the healthcare system.

A simple form is available online for filling in the details of good practice. It should not take longer than 30 minutes to complete this.

<https://www.surveymonkey.com/r/TRZ2Y9J>

Otherwise you can send us information by email to policy@eu-patient.eu

Make a video

Make a video (alone or in a team) to tell us what you are doing on patient empowerment or what you ask from your decision-makers, healthcare professionals or others. You can also follow EPF on YouTube and share our videos.

Find an ambassador

Is your patient organisation working with an excellent, committed and truly patient-centred healthcare professional whom you would like to nominate as “patient empowerment ambassador”? Let us know!

Initiate a dialogue or an activity with other stakeholders

Patient organisations are drivers of advocacy and patient empowerment, but in order to make real changes happen everyone who supports patient empowerment needs to be active: family carers, medical and other health professionals, national regulators, academic researchers the healthcare industry, health insurance providers and anyone else who is interested in building a better EU health system.

You can ask your “friendly” stakeholders to look at the **EPF Roadmap** and identify one area where they can make a difference, and possibly initiate a joint project.

Use social media and connect with EPF

There are a number of hashtags being used around patient empowerment: clearly, #patientempowerment is a useful one, as are #patientsinvolved, #patientsincluded, #patientengagement, #patientexperience, #codesign, #PPI [patient and public involvement], and others.

You can follow EPF on Twitter @eupatientsforum. We will be happy to act as multiplier of your messages! Do tag our twitter handle @eupatientsforum so that we will see your tweets, and to address us directly.

5 Whom to contact

If you need further information about this toolkit or any other aspect of EPF's work, please feel free to contact our Secretariat.

European Patients' Forum
Chaussée d'Etterbeek 180
1040 Brussels
Belgium

Telephone: + 32 (0)2 280 23 34
Email: info@eu-patients.eu

A contact form is available at <http://www.eu-patient.eu/contact-us/>

If you wish to use EPF's materials and are not from an EPF member organisation, please email: communications@eu-patient.eu

6 Selected Information and Resources

Below you will find links to a wide range of information, publications and resources that we have found potentially interesting, with topics ranging from lay-friendly information to patient safety and implementation of shared decision-making. The list does not purport to be comprehensive. Some organisations have produced a lot of material, only some of which is included here considering both relevance and how recent the material is. All the resources included here are publicly available.

Please note that the inclusion of a resource of information source from external stakeholders on these pages does not mean that EPF formally endorses that resource or the information provider.

The list is currently quite English-language dominated; we would welcome more links to resources in other languages. The list will be updated regularly with more information.

EPF patient empowerment resources

Resource	Source	Year	Language	Available at
Infographic: What Is Patient Empowerment?	EPF	2015	ALL EU languages	Link
Patient empowerment video and interviews with patient representatives	EPF	2015	EN	Link
The Patient's Charter on Patient Empowerment	EPF	2015	EN, EL, ES, FR, GR, LT, NL, RO, SK	Link
Roadmap for Action on Patient Empowerment	EPF	2016	EN	Link
Set of slides on patient empowerment (PDF)	EPF	2017	EN, FR	Link
Presentations and report from the EPF Patient Empowerment Conference	EPF	2015	EN	Link
Presentations and report from the EPF conference on patient empowerment and involvement in patient safety	EPF	2016	EN	Link
EUPATI Toolbox of lay-friendly information for patient advocates on medicines research development	EUPATI	2017	EN, DE, ES, FR, IT, NL, PL, RU	Link

EUPATI list of National Platforms	EUPATI	2017	EN	Link
EUPATI webinars – all webinars on one page	EUPATI	2017	EN	Link
Report on the added value of patient organisations	EPF	2017	EN	Link
Value+ Toolkit for patient organisations	EPF	2009	EN, BG, ES, DE, FR, LT	Link
Value+ Handbook for project leaders	EPF	2009	EN	Link

Resources by patient organisations

Resource	Source	Year	Language	Available at
A narrative for person-centred coordinated care	National Voices, UK	2013	EN	Link
Description: This narrative describes what good quality integrated care looks like from the point of view of anyone who needs access to multiple services over time. It was adopted as a national definition for integrated care by all the system leading bodies in England, including the Department of Health in a national 'Shared commitment' document.				
My life, my support, my choice. A Narrative for person centred coordinated care and support for children and young people with complex lives	National Voices, UK	2015	EN	Link
Description: This fifth narrative on person-centred, coordinated care describes some outcomes and success factors in the care and support of children and young people with complex lives, from their perspective and that of the people who are important to them.				
Every Moment Counts. A Narrative for Person Centred Coordinated Care for People Near the End of Life	National Voices, UK	2015	EN	Link
Description: The fourth narrative on person-centred, coordinated care describes some critical outcomes and success factors in end of life care, support and treatment, from the perspective of the people who need that care, their carers and families.				
I'm Still Me. A Narrative for Coordinated Support for Older People	National Voices, UK	2014	EN	Link
Description: The third narrative on person-centred, coordinated care describes the way older people want high quality coordinated care to support them, from their perspective.				
No assumptions. A narrative for personalised, coordinated care and support in mental health	National Voices, UK	2014	EN	Link

Description: The second narrative on person-centred, coordinated care describes some critical outcomes and success factors in the care, support and treatment of people who use mental health services, from their perspective.				
Involving patients and citizens: I Statements for research and innovation	National voices, UK	2016	EN	Link
Description: The processes of research and innovation in health can be complex, opaque, and are driven by a mix of scientific, commercial and regulatory factors that do not necessarily align with what really matters to people. These “I statements” set out patient and citizen expectations, and can be used by those involved in research and innovation to help meet these expectations. They set a standard for what ‘good’ looks and feels like.				
Principles of integrated care	National voices, UK	2013	EN	Link
Description: 12 principles of integrated care developed on the basis of experiences of service users as well as research evidence. Designed for use in the UK setting, nevertheless many of the principles are widely applicable.				

Resources by others – academic studies, policy documents, guidelines etc.

Resource	Source	Year	Language	Available at
Core quality criteria for information to patients	High-level Pharmaceutical Forum	2008	EN	Link
Description: This document sets out the following criteria for high-quality information to patients on diseases and treatment options: (1) objective and unbiased; (2) patient-oriented; (3) evidence-based; (4) up to date; (5) reliable; (6) understandable; (7) accessible; (8) transparent; (10) relevant and appropriate; (11) consistent with statutory information.				
Methodology for use of the core quality criteria for information to patients	High-level Pharmaceutical Forum	2008	EN	Link
Description: This document sets out quality requirements for information material on diseases and treatments to prevent any promotion and to ensure the confidence of patients. Its main purpose is to support the development of good quality information according to the “core quality principles” and to help patients distinguish high-quality from poor-quality information.				
Health literacy. The solid facts.	WHO	2013	EN	Link
Description: This publication makes the case for policy action to strengthen health literacy, presenting evidence in support of a whole-of-society approach considering both individual health literacy and the complexities faced by people. It presents practical and effective ways public health and other sectoral authorities and advocates can take action to strengthen health literacy in different settings, including education, workplace, marketplace, health system, media and the political arena.				
The EMPATHIE study, final summary report	European Commission	2014	EN	Link

Description: This final report presents the findings of the EMPATHIE study as well as relevant conclusions, recommendations and scenarios for collaborative action on patient empowerment. EPF led the work package concerning stakeholder collaboration and future scenarios.				
Educational framework for health professionals for managing and supporting medication adherence (shared decision-making, communication)	Project “Ascertaining Barriers to Compliance” (ABC) funded by European Commission (FP7)	2011	EN	Link
Description: Decisions about taking medicines ultimately lie with patients, so health professionals need to engage with patients to manage and support medication adherence. Health professionals need appropriate education to do this. This document comprises a competency framework, curriculum, diagnostic tool for competence assessment, and a reading list. The competency framework includes listening actively to the patient; communicating to help patients interpret information in a way that is meaningful to them; defining and agreeing purpose with the patient; recognising and treating the patient as an individual; exploring various options, expectations and preferences with the patient; co-deciding on the best management strategy; and supporting the patient with medication taking.				
Guideline for Improving the patient experience of care	NICE/NHS, UK	2016	EN	Link
Description: This guideline incorporates five principles: 1. Knowing the patient as an individual, so that their beliefs, concerns and preferences inform their care; 2. Dignity, kindness, respect and honesty as essential requirements of care; 3. Tailoring services for each patient, e.g. according to their ability to access services and their coexisting conditions; 4. Continuity of care and relationships, coordination, information exchange; 5. Enabling patients to actively participate in their care, e.g. through shared decision-making support.				
Measuring patient experience. Evidence scan	The Health Foundation, UK	2013	EN	Link
How has the experience of patients and carers been measured in healthcare? What are the pros and cons of measuring improvement over time? This evidence scan provides an accessible overview of the range of methods that have been used to measure patient experience in order to help practitioners, planners and researchers consider the best approaches for local improvement initiatives.				
Measuring what really matters. Thought paper	The Health Foundation, UK	2014	EN	Link
This paper by Dr Alf Collins describes the principles of person-centred care and activities that a person-centred system should undertake in different contexts, by introducing a hypothetical patient, “Dorothy”. It describes how to think about constructing measurement systems for use in each of these contexts to measure what really matters to Dorothy.				
Helping people shared decision-making. A review of the evidence	The Health Foundation, UK	2012	EN	Link
This report brings together evidence showing that shared decision-making improves patient’s satisfaction, involvement in their care and knowledge of their condition. It highlights the need for approaches that support patients to have the confidence, information and support to participate in decisions about their health and healthcare. It shows that policy statements alone will not put shared decision making into practice – active steps are needed to change the behaviour of both healthcare professionals and patients. This				
Supporting self-management.	The Health Foundation, UK	2016	EN	Link

Description: this is a guide for people who support patients living with long-term conditions or help people avoid these conditions, using person- and community-centred approaches. This can include professionals, volunteers, peer supporters, carers, and patient themselves. It is action-focused and features low-tech, pragmatic and manageable activities. This guide offers a framework for understanding and changing behaviour, and real-world examples of how these changes happen in practice.				
Person-centred care made simple	The Health Foundation, UK	2014	EN	Link
Description: This guide provides a quick and clear explanation of the principles of person-centred care, why it is important, how it has developed, and some examples to help those considering putting person-centred care in to practice. It is intended for anyone interested in health and health care, including professionals and patients.				
When doctors and patients talk: making sense of the conversation	The Health Foundation, UK	2012	EN	Link
Description: This report explores the main form of interaction between a patient and a clinician – the consultation. It offers an analysis of the relationship, identifying the “mutual fears that drive doctors and patients and the invisible structures that are natural to the doctor but hidden from the patient” and describes the potential for a more nuanced model for the consultation.				



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