** **

**EPF Campaign on Patient Empowerment:**

**Roadmap for Action**

draft for consultation, please do not share

Contents

[Foreword by EPF President (tbc) 3](#_Toc447113214)

[Introduction 4](#_Toc447113215)

[Priority area 1: High-level actions to promote patient involvement 7](#_Toc447113216)

[Priority area 2: Health literacy and information for patients 8](#_Toc447113217)

[Priority area 3: Supporting shared decision-making 10](#_Toc447113218)

[Priority area 4: Self-management support 11](#_Toc447113219)

[Priority area 5: Patient-driven technology solutions 12](#_Toc447113220)

[Priority area 6: Patient involvement in patient safety 13](#_Toc447113221)

[Priority area 7: Improving the quality of care 15](#_Toc447113222)

[Priority area 8: Patient-centred innovation/ therapeutic R&D and regulation 17](#_Toc447113223)

## Foreword by EPF President (tbc)

To be added.

## Introduction

Patient empowerment is at the root of our vision and mission, as reflected in the European Patients’ Forum’s 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.

The term patient empowerment is often used interchangeably with others such as patient involvement or patient-centred care. Sometimes, it is perceived simply as the use of technology by patients. A recent EPF briefing paper (2015) clarifies these concepts from the patient perspective.[[1]](#endnote-1) We use the following definition of patient empowerment:

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.”

Aspects of empowerment can include self-efficacy, self-awareness, confidence, coping skills, health literacy, etc. It can be seen as a goal as well as a process, and it is a complex concept that is context-dependent. Patients’ empowerment is affected by the people, processes, organisations and structures that they come into contact with and can fluctuate with time.

In healthcare, at the individual level, (dis)empowerment often manifests in the patient-professional relationship; at organisation level, in care processes or the design of the care environment. At macro-level, factors that contribute to (dis)empowerment can include (the lack of) information to patients, implementation of patients’ rights, opportunities for patients to participate in health policy, and transparency of the system.

Patient empowerment and the challenge of chronic diseases

Chronic diseases are conditions of long duration and generally slow progression, which result in significant morbidity and loss of healthy life years. They represent the major share of the burden of disease in Europe[[2]](#endnote-2), affecting more than 80% of people aged over 65. An estimated 70-80% of healthcare costs – around €700 billion – are currently spent on chronic diseases.[[3]](#endnote-3) Given that the ageing population of Europe, addressing chronic diseases is one of the key objectives of EU health policy for the next years.

For an effective strategy on chronic diseases, all the aspects of physical and mental health including health promotion, primary and secondary prevention, and patient-centred chronic disease management should be seen holistically as a continuum where all the elements play a complementary and mutually supporting role.

The recognition that healthcare systems should change to improve not only their cost effectiveness and long-term sustainability but also their effectiveness in providing high-quality care, represents a paradigm shift. Care will need to shift from an acute, hospital-centric environment to a community-based, integrated, longer-term model. In this model, patients are no longer passive recipients of care but active partners and ultimately “co-producers” of health.[[4]](#endnote-4)

There is a political acknowledgement at EU level that patients should be “at the centre” of healthcare systems and that to achieve this, patients' representative organisations should be part of healthcare-related policy and decision-making.

Citizens' empowerment is a core value of the EU Health Strategy Together for Health. In 2006 the Council recognised patient involvement as one of the shared operating principles of European health systems. EU co-funded projects, such as Value+, PatientPartner and EUPATI, have shown the benefits of patient engagement. Patient-centred chronic disease management with focus on patient empowerment was identified as a priority in the reflection process on chronic diseases initiated.[[5]](#endnote-5) Patient-centredness is recognised as a core component of quality care.[[6]](#endnote-6) Patient-centred care models have been shown to be cost-effective as well as improve the patient experience and health outcomes.[[7]](#endnote-7) Patients living with chronic conditions are “experts by experience” whose perspective on disease and care is unique. When they are genuinely involved in healthcare decisions and their preferences are listened to and acted on, the result is better health outcomes, more engaged patients and, potentially, lower costs.[[8]](#endnote-8)

Despite this accumulating evidence base, there is still no consistent and comprehensive approach in Europe to patient empowerment. This extent this has no doubt to do with the different structures and cultures of European health systems, but also lack of awareness and resources; lack of knowledge on how to meaningfully involve patient groups; and a patient community with different levels of capacity across the EU.

Collective patient empowerment, through the meaningful involvement of patient representatives and organisations in health policy, service design and evaluation with the aim to improve the system, will be the key to fostering patient empowerment in all EU health systems.

What we hope to achieve with this Roadmap

This Roadmap for Patient Empowerment has been developed by the European Patients’ Forum in the context of our Campaign on Patient Empowerment.[[9]](#endnote-9) It accompanies the *Charter on Patient Empowerment*, transforming the fundamental principles expressed in the Charter into concrete actions the patient community wishes to see happening in practice. It consists of eight *priority areas*, reflecting the priorities of the Charter as well as the recommendations from the EMPATHIE study (2014) and proposes a number of *key actions* in each area.

The EMPATHIE stakeholder survey confirmed a strong interest to collaborate on patient empowerment at European level. European collaboration was seen as having two clear objectives:

1. achieving concrete improvements in healthcare, taking as a starting point patients’ self-defined needs and expectations (the overall goal);
2. finding the best working methods to reach that goal.

The study recommended the formulation of a *European strategy on patient empowerment* as a starting point. This Roadmap hopes to go some way towards identifying priority areas of action to be included in such a strategy.

We recognise that no one approach on its own will be capable of addressing all aspects of empowerment, in all different contexts as empowerment is complex and influenced by many factors. The priority areas and actions in this Roadmap are highly complementary and can point towards multiple paths towards the goal of achieving European health systems that are high-quality, patient centred, participatory and sustainable.

## Priority area 1: High-level actions to promote patient involvement

The Alma Ata declaration (1978) defined civic involvement in healthcare as both a right *and* a duty. Patients’ participation in health policy is both a fundamental democratic principle and an expression of the transparency and accountability of the system towards its users. Patient organisations are accountable to their patient constituencies and effectively channel the collective voice of patients into effective policy advocacy, whether at local, regional, national, EU or global levels.

Patient organisations represent a constituency of patients and put forward views arrived at through a consultative, democratic process. They perform a valuable public service, including through their ongoing collaboration with regulatory institutions and Health Technology Assessment bodies. They also function as community support organisations at grassroots level. Nevertheless, they often suffer from chronic lack of resources and staff.

The following actions should be taken to ensure that patient organisations are recognised as key stakeholders and members of the public health community; that policies which affect patients directly or indirectly are developed with the meaningful participation of patient organisations; and that patient organisations are appropriately resourced and supported to accomplish their role.

|  |  |  |
| --- | --- | --- |
| **Action** | **Objective/example of achievement** | **Time-frame** |
| EU Strategy on Patient Empowerment for sustainable, participatory health systems, including action plan for health literacy and strategies for vulnerable groups. | European Commission to lead the process with a balanced participation of all relevant stakeholders. | Medium |
| Improved support for patient organisations active at European level through EU “core grants”. | Adjustment of the current financial criteria to enable more patient groups to become eligible. | Short - medium |
| Exploration of innovative, ethical ways of funding national patient organisations from multiple sources so they can accomplish their role effectively whilst maintaining their independence. | Member state governments, patient organisations, private sector – to develop a support strategy as a collaborative effort? | Medium - long |
| Collection of good practices and initiatives on patient empowerment and patient organisations’ involvement at local and national levels for sharing and mutual learning. | An online repository with information, experiences, tools and resources, openly accessible. (Implemented as a project?) | Short -medium |

## Priority area 2: Health literacy and information for patients

People in 21st century society are increasingly asked to take responsibility for their own health and well-being, while confronted with huge amounts of complex and sometimes contradictory information. In this context, health literacy is seen as both a dimension of empowerment and a critical strategy towards empowerment health equity.[[10]](#endnote-10)

Health literacy encompasses accessing, understanding and evaluating health-related information, as well as transforming it into appropriate actions in everyday life.[[11]](#endnote-11) Low health literacy has a negative impact on people’s health and is related to increased costs to the healthcare system.[[12]](#endnote-12)

The Third Health Programme states that patients “need to be empowered, inter alia by enhancing health literacy, to manage their health and their healthcare more pro-actively, to prevent poor health and make informed choices. The transparency of healthcare activities and systems and the availability of reliable, independent and user-friendly information to patients should be optimised.”[[13]](#endnote-13)

The 2012 European Health Literacy study showed that nearly half of respondents had limited health literacy.[[14]](#endnote-14) In recognition of this challenge, an informal group of patients, researchers, health professionals and industry published a consensus paper calling for health literacy to be a priority in EU policy.[[15]](#endnote-15) A European mapping study published in June 2015 showed that whilst interest in health literacy is increasing, important gaps remain in evidence.[[16]](#endnote-16) Major EU-funded research projects also recently concluded.[[17]](#endnote-17)

Despite the accumulating evidence-base, there is no coherent EU strategy on health literacy or health-related information for patients and citizens.

Patients need the right information, in the right amount, at the right time. Information should be available from the most basic to the most complex, according to a patients’ needs and wishes at any given time. Information must be of high quality: accurate, comprehensive, understandable, evidence-based. Ideally, information targeted at patients should be developed together with patients.[[18]](#endnote-18)

|  |  |  |
| --- | --- | --- |
| **Action** | **Objective/example of achievement** | **Time frame** |
| Promote access to accurate, objective, unbiased, user-friendly and scientifically up-to-date information relevant to patients’ needs, on all aspects of health from promotion and prevention to disease management and therapeutic options based on patients’ identified needs and preferences. |  |  |
| Existing core quality criteria for information to patients should be applied at all levels. |  | Short |
| Support the visibility and accessibility of good quality online health-related information. | “Quality seal” for online information resources, based on core quality principles. | Medium |
| Review and evaluation of all existing EU legislation and non-legislative frameworks pertaining to information to patients. | An analysis of existing frameworks and gaps, as well as existing resources. | Short - medium |
| Collection of good practices and examples of application of health literacy principles, especially for making the healthcare system organisations more easily navigable and understandable and including strategies for people with low health literacy. | These could be included as part of the repository of good practices on patient empowerment. | Medium |
| Patients’ free access to their own health records should be implemented across the EU. | Monitoring of patients’ right to access their health records to be included as part of monitoring of the implementation of the EU cross-border healthcare directive. | Medium |
| Regulatory information on medicines, including their benefits and risks, to be available in simple language and lay-friendly format. | The European Medicines Agency to review existing guidelines for the patient information leaflet (PIL) and explore the feasibility of introducing a complementary “fact box” of concise information. | Short – medium |
| Embed health literacy in all policies, including education, food, urban planning, social protection, and employment. | A symposium at European level “health literacy in all policies”?  Sharing of existing tools such as the “blueprint for employers”?  Ideas welcome | Medium - long |
| Implement a regular EU Health literacy survey across all EU Member States to collect comparative data and monitor changes over time. | European Commission / Eurobarometer based on the validated instrument from the EU Health Literacy Survey (HLS). | Short-long |

## Priority area 3: Supporting shared decision-making

Shared decision-making is an intrinsic part of patient empowerment. To become engaged in managing their health, patients need to be empowered to make decisions about their care in partnership with the (team of) healthcare professionals. The EMPATHIE study shows that the skills, knowledge and importantly attitudes held by professionals are key factor in this. Shared decision-making is also the least researched area of patient empowerment.

Future training will need to be adapted to patient-centred, integrated chronic disease management models, but currently practising professionals’ attitudes and skills may also need updating. At the same time, we recognise that the working environment sometimes does not encourage health professionals to engage with patients meaningfully (e.g. due to pressures of time or workforce shortages).

Patient-centred skills such as shared decision-making, listening, supportive and effective communication, empathy and partnership are “soft skills” that are not specific to any medical condition. New roles and skills may also need to be developed based on patients’ expressed needs, values and preferences; such as care co-ordination, coaching, or patient advocacy.

The Expert Panel on Effective Ways of Investing in Health (EXPH) in its recent report made a high-priority recommendation “to promote the training of health professionals in their new role of ‘trainers’ for patients with chronic conditions and in addition develop ways, means, time and motivation for professionals to learn better communication skills to engage and involve patients in their care.”[[19]](#endnote-19) Patients should be much more involved in professional training and the development of curricula than they are now.

There are a number of existing frameworks at EU level where specific actions could be situated to support national policy, such as the EU Action Plan on the Health Workforce and the European Commission’s Expert Group; and the Expert Group on patient safety and quality of care.

|  |  |  |
| --- | --- | --- |
| **Action** | **Objective/example of achievement** | **Time frame** |
| Map patients’ needs for professional education. | Patient organisations with academics? Project |  |
| Develop a core set of “soft” non-medical competences for integration into professional training curricula. | A task force with patients, professionals, academia? Taking forward the recommendation from empathie. |  |
| Collect and share innovative practices, e.g. using patient stories, simulations, patient participation in designing training curricula. | Such practices could be shared as part of the patient empowerment repository. |  |
| More research into shared decision-making, patient decision-aids, and particularly the transferable, non-disease specific aspects should be funded. | Horizon 2020? |  |

## Priority area 4: Self-management support

Patients with chronic conditions manage their condition mostly themselves in the home and in the community.[[20]](#endnote-20) they do this with and without support. However, to maximise the benefit of self-management patients do need effective support. This can be, but is not necessarily, through the use of technology.

EPF fees self-management in its wider sense as a holistic approach providing the appropriate support and tools for each person’s individual needs and preferences. Through this patients can develop the confidence, self-efficacy and skills to take control of the daily management of their illness and attain the greatest possible quality of life. In this sense, self-management support also aims to make the best use of all available resources in the system – including the knowledge, skills and motivation of the patient.[[21]](#endnote-21)

There is good evidence that supported self-management improves health outcomes and reduces costs.[[22]](#endnote-22) The importance of self-management support has long been understood, and in many disease areas (e.g. diabetes, respiratory diseases) models and tools have been promoted and researched for decades. In some disease-areas a so-called guided self-management approach is widely used.[[23]](#endnote-23)

The Chronic Care Model recognises the central role of the informed, motivated patient alongside with a prepared and proactive care team. At the heart of this model is the importance of providing patients with effective self-management support for long-term health problems.[[24]](#endnote-24) The Stanford chronic disease self-management programme is based on the chronic care model.[[25]](#endnote-25) Yet, overall, such services are still not available to patients consistently across countries and disease areas.

|  |  |  |
| --- | --- | --- |
| **Action** | **Objective/example of achievement** | **Time frame** |
| Evidence base self-management education should be made widely available. | ? ENOPE how can we make such programmes more accessible, given the restrictions on budgets? Innovative ways of delivering them? Community involvement? |  |
| A better understanding of cross-disease aspects of self-management support is needed. | ? ENOPE. Research? |  |
| Development of integrated care models and pathways, with the patient and family as active participants, and which include self-management support and also link health with social care and support. | Project? Does an overview exist? |  |
| EU level guidance on promotion of self-care, including communication and policy development. | Two ongoing EU- funded studies (PISCE and PRO-STEP) will deliver their results by 2018. | Short |

## Priority area 5: Patient-driven technology solutions

eHealth and mHealth are rapidly emerging areas of healthcare; while they are often seen as potential solutions to increase efficiency and cut costs, they also have considerable potential to support patients’ empowerment and adoption of an active and responsible role for their health. Such tools can provide self-management support and motivation; patients can also monitor their condition at home through wearable technology. They could add data from their own observations to a global electronic health record, shared with health professionals. Such a health record can also contain information on general health such as diet and exercise.

Mobile apps offer potential for developing information and diagnostic tools, possibilities to “self-quantify” as well as new modalities of care, blurring the distinction between the traditional provision of clinical care by physicians, and the self-administration of care.[[26]](#endnote-26) However, most available tools at the moment target the consumer market; patients who use mHealth are a minority, and they often do not find it easy to know which app would be right for them. The European Commission’s eHealth Action Plan (2012) identified lack of trust and training as being among key barriers to uptake of technology.[[27]](#endnote-27)

Often, new devices are introduced as “empowering” patients, when patients have not been consulted in the development of the “innovation” and there is no evidence that the new tool meets an identified patient need. Therefore, in order for these tools to realise their potential, their development needs to be user-driven rather than technology-driven.

|  |  |  |
| --- | --- | --- |
| **Action** | **Objective/example of achievement** | **Time frame** |
| Based on findings to date , targeted research and development to address the lack of user-friendly tools and services. |  |  |
| Develop quality standards and guidelines for the development and use of mobile health applications, including patient engagement from the start. | Note: this is already happening. Patient involvement? |  |
| Develop indicators to measure added value of these applications – from the patients’ and the health systems’ perspective |  |  |
| Develop education resources and tools to support use of eHealth and mHealth by patients and by professionals. |  |  |
| There are a number of frameworks for policy and funding of eHealth at European level, but no specific collaboration focused on empowerment aspects. | The European Innovation Partnership on Healthy and Active Ageing (EIP-AHA) could provide a framework for development, sharing and evaluation of patient-driven solutions to support patient empowerment. |  |

## Priority area 6: Patient involvement in patient safety

Patient safety is both a goal (a state of being that is free from unnecessary harm) and a practice (processes and structures that aim to make healthcare safer). Patient safety is a fundamental attribute of quality of care. Safety covers everything from harm caused as a result of a wrong diagnosis, clinical procedure or decision, to the side-effects of drugs, hazards posed by medical devices or sub-standard products, human shortcomings, and system errors, in all kinds of health care settings. *(some figures can be added in the final layout – “fact box”)*

Addressing safety means ensuring that the healthcare system or organisation takes all possible measures to prevent vulnerabilities, and when errors do happen they are recognised and fully investigated and lead to action in order to prevent future errors. Developing a “patient safety culture” is vital[[28]](#endnote-28) and this involves the recognition that safety is everyone’s business – including patients and their families’.

Patients are a source of information about failures and gaps in the system during the “patient journey”. They can help improve their own safety and that of others, for example by becoming health literate and actively involved in managing their own condition. They can also help improve services overall to make them more patient-centred. Involving patients implies a change in medical culture where professionals, managers, and policy-makers need to listen to patients, take their observations and concerns seriously, accept them as equal partners and encourage feedback and involvement at all levels. However, involving patients should not mean shifting the burden of responsibility on them in an inappropriate way.

|  |  |  |
| --- | --- | --- |
| **Action** | **Objective/example of achievement** | **Time frame** |
| Enhance the capacity of patients and families to contribute to better patient safety by implementation of paragraph 2 (c) of the 2009 Council Recommendation on patient safety (2009/C 151/01). | EPF working group together with experts will develop a set of “core competencies” in 2017. | Short |
| Develop best practice for dealing with the aftermath of adverse events from the patient perspective, including transparency, communication with patients and families, involving patients and families in root cause analysis, and action for improvement. | This issue will be addressed in EPF’s conference on patient safety in 2016. |  |
| All Member states should implement the 2009 CR and involve patient organisations and representatives in the development of policies and programmes on safety, including prevention of healthcare associated infections. |  |  |
| A permanent EU framework for collaboration on patient safety and quality should be ensured, involving member states and stakeholders and building on the achievements of the PASQ Joint Action. | EU work programme – health programme. |  |
| Empathie recommendations on transparency of quality and safety information | implementation of the cross-border healthcare directive |  |

## 

## Priority area 7: Improving the quality of care

*Patient or person-centredness* is increasingly recognised as a core component of quality in healthcare. Patient-centredness involves not only being responsive to patients’ needs and preferences, but also empowering patients and their families to enable the participation as active and equal participants in the care process. It also requires a seamless integration of the different aspects of health (and social) care around families’ needs.

An accurate elicitation of the patients’ needs and preferences is a fundamental starting point for a re-design of care in order to become more patient-centred. Indicators for healthcare quality exist, such as those collected by the OECD and the European Community Health Indicators (ECHI); however there is currently no agreed way of measuring patient-centredness or patient empowerment – partly because the concept is not amenable to quantification.

There is a need for more systematic understanding about how patients define “quality” in healthcare, and how patient-centredness could be measured. The patient experience is an important aspect that should be included beside clinical indicators in evaluations of healthcare quality. This implies meaningful, and if necessary qualitative, measures based on patient feedback that can be analysed, acted upon and actually lead to better care.

Transparent and comparable information is one important tool to facilitate informed decision-making, accountability and improvement in healthcare quality. Transparency in healthcare is being driven by the recognition of the people’s right to information, the desire to bring about continuous improvement, and to make it easier for patients to navigate the system. EU Directive 24/2011 on the application of patients’ rights in cross-border healthcare now requires Member States to make available information to patients on quality and safety standards and guidelines. In order to be meaningful to patients, the information must be presented in a way that is relevant, comparable and understandable to a layperson.

|  |  |  |
| --- | --- | --- |
| **Action** | **Objective/example of achievement** | **Time frame** |
| Patient-centredness should be included as a key metric under the EU Health System Performance Framework (HSPA). |  |  |
| Appropriate measures/indicators should be selected and new ones developed where necessary, including qualitative evidence. | OECD to analyse patient reported outcomes and patient experience measures (PROMs and PREMs) |  |
| Healthcare organisations should put in place mechanisms to collect feedback from patients and families. |  |  |
| The EU should fund research on innovative healthcare organisation and delivery models (e.g. integration of care, participatory medicine, patient involvement, and organisational culture change). | Horizon 2020 |  |
| EU guidelines should be developed on how to provide transparent, comparable and understandable information on safety and quality of care to patients. | The guideline can support implementation of the cross-border healthcare directive (National Contact Points). |  |
| Educational resources should be developed for patients on how to interpret quality and safety data. | Possible opportunity for partnering between patient organisations and quality experts |  |

## Priority area 8: Patient-centred innovation/ therapeutic R&D and regulation

Advances in medicine only possible with the voluntary participation of patients. Patients therefore have a moral right to be involved in how research is developed, managed and evaluated. Involvement also leads to better quality research results: patients’ experiential knowledge is an important complement to researchers’ scientific knowledge.

Patients’ priorities are often different from those of researchers, medical professionals or industry. Not everything that is new can be considered innovative or novel. In EPF’s view “innovation” implies new products that bring added value for patients’ health or quality of life. It is important to define a clear policy at European level towards fostering and rewarding innovation in this positive sense. This conversation should take place with the involvement of all relevant stakeholders, including patients and payers.

To ensure that innovation brings real value to patients, patient involvement needs to be adopted as a strategic approach and integrated across the entire innovation chain at EU and national levels. The WHO Priority Medicines report update (2014) recognised that there was a need to develop frameworks for ensuring patient priorities guide R&D.

Patient involvement in the regulatory process is indispensable, particularly with the emergence of novel, more flexible approaches to authorisation of new products, such as conditional marketing authorisation and adaptive pathways, which promise faster patient access but need careful balancing of the related uncertainties, benefits and risks. The EMA model for involving patients and consumers is widely seen as an example of good practice with potential for replication, but could be taken up more proactively by national authorities.

|  |  |  |
| --- | --- | --- |
| **Action** | **Objective/example of achievement** | **Time frame** |
| Develop frameworks for meaningful patient involvement across the innovation chain, in collaboration with relevant parts of the EU commission and stakeholders – from priority setting in research designed to the regulatory processes, cost benefit assessments, pricing and reimbursement, and the use and reuse/collection of patient data in an ethical way. |  |  |
| Develop a coherent patient engagement strategy within the innovative medicines initiative (IMI). |  |  |
| Continued emphasis on patient education and continued patient education akin to CPD on therapeutic innovation building on EUPATI | (More concrete) through setting up national eupati platforms? |  |
| A dedicated reference to patient involvement in HTA and specific aspirations for JA 3 | Vale |  |
| Closer links between initiatives in the pharmaceutical / med-tech and IT industry, which are often disparate , under a common patient empowerment umbrella. | Walter/Jan |  |
| Academic and industry-led research should prioritise issues that patients consider most important. | Research applications with meaningful patient involvement in defining the research questions and protocols, should be prioritised for funding. |  |
| The European Medicines Agency’s principles of patient involvement should be adopted by national Medicines Agencies, particularly in member states were there is currently little patient involvement. | The network of medicines agencies can play a valuable role in sharing and mutual learning, *inter-alia* through closer links with the Patient and Consumer Working Party (PCWP). |  |

## References

1. EPF Background Brief: Patient Empowerment (May 2015). Available at [www.eu-patient.eu/globalassets/campaign-patient-empowerment/briefing\_paperpatient-empowerment\_final\_external.pdf](http://www.eu-patient.eu/globalassets/campaign-patient-empowerment/briefing_paperpatient-empowerment_final_external.pdf) [↑](#endnote-ref-1)
2. Herein after ‘Europe’ substitutes the European Union, as in certain contexts it is more appropriate to refer to Europe in geographical terms. [↑](#endnote-ref-2)
3. Final report of the reflection process: Innovative approaches for chronic diseases in public health and healthcare systems, 11 November 2013 [↑](#endnote-ref-3)
4. e.g. Realpe and Wallace, 2010 [↑](#endnote-ref-4)
5. reflection process final report, 2013. [↑](#endnote-ref-5)
6. R Jayadevappa and S Chhatre, “Patient Centered Care - A Conceptual Model and Review of the State of the Art”, *The Open Health Services and Policy Journal*, 2011, 4, 15-25) [↑](#endnote-ref-6)
7. Parsi et al. 2011, Olsson et al. 2009, Mulley et al. A 2012 [↑](#endnote-ref-7)
8. Mulley et al. Patients’ preferences matter: Stop the silent misdiagnosis. The King’s Fund, 29 May 2012; Arterburn et al. “Introducing decision aids at Group are you Health was linked to sharply lower hip and knee surgery rates and costs”, *Health Aff* (Millwood). 2012 Sep;31(9):2094-104; Veroff D, Marr A, Wennberg DE: “Enhanced Support For Shared Decision Making Reduced Costs Of Care For Patients With Preference-Sensitive Conditions”. Health Affairs, February 2013, vol. 32, no. 2, 285 [↑](#endnote-ref-8)
9. charter available at [↑](#endnote-ref-9)
10. EMPATHiE. Empowering Patients in the Management of Chronic Diseases. Final report, 10 November 2014; Wallerstein, N (2006) “What is the evidence on effectiveness of empowerment to improve health?” Copenhagen, WHO Regional Office for Europe (Health Evidence Network report). [↑](#endnote-ref-10)
11. Sørensen et al. “Health literacy and public health: A systematic review and integration of definitions and models”, *BMC Public Health* 2012, 12:80. [↑](#endnote-ref-11)
12. Eichler, K et al. (2009). “The costs of limited health literacy: a systematic review”, *Int J Public Health*, 2009;54(5):313-24; World Health Communication Associates 2010; WHO Europe 2013, Health Literacy: The Solid Facts. [↑](#endnote-ref-12)
13. (Regulation (EU) No 282/2014, recital 12) [↑](#endnote-ref-13)
14. Countries: Austria, Bulgaria, Germany, Greece, Ireland, The Netherlands, Poland and Spain. HLS-EU Consortium (2012): Comparative Report of Health Literacy in Eight EU Member States. The European Health Literacy Survey HLS-EU (first revised and extended version, dated 5 July 2013). [↑](#endnote-ref-14)
15. “Making health literacy a priority in EU policy”. Consensus paper by CPME, EPF, Maastricht University and MSD. June 2013. [↑](#endnote-ref-15)
16. “Study on sound evidence for a better understanding of health literacy in the European Union”. RfS Chafea/2014/health/01. Final Report, June 2015. [↑](#endnote-ref-16)
17. [www.irohla.eu/home/](http://www.irohla.eu/home/) and [www.diabetesliteracy.eu](http://www.diabetesliteracy.eu) [↑](#endnote-ref-17)
18. A set of quality principles for information to patients was developed by the EU High-Level Pharmaceutical Forum in 2008, but is not systematically used. See the “Core quality principles adopted by the EU High-Level Pharmaceutical Forum (2008) available at <http://ec.europa.eu/DocsRoom/documents/7593?locale=en> [↑](#endnote-ref-18)
19. EXPH, 2014, p. 71. [↑](#endnote-ref-19)
20. <http://www.eu-patient.eu/whatwedo/Policy/A-Z-list-of-topics/> [↑](#endnote-ref-20)
21. EPF position paper on adherence and concordance (2015). [↑](#endnote-ref-21)
22. De Silva (2011) “Evidence: Helping people help themselves. A review of the evidence considering whether it is worthwhile to support self-management”. The Health Foundation, 2011. [↑](#endnote-ref-22)
23. E.g. in management of allergy, asthma and COPD in the Nordic countries and the UK (European Federation of Allergy and Airways Disease Patients’ Associations). [↑](#endnote-ref-23)
24. Bodenheimer et al (2002) “Improving primary care for patients with chronic illness. The chronic care model, part 2.” JAMA 2002; 288: 1909-1914; Wagner, EH (1988) “Chronic disease management: what will it take to improve care for chronic illness?” Eff Clin Pract. 1998 Aug-Sep; 1(1):2-4. [↑](#endnote-ref-24)
25. <http://patienteducation.stanford.edu> [↑](#endnote-ref-25)
26. COM(2012)736 final, p. 9 [↑](#endnote-ref-26)
27. See also project “Chain of Trust” final report, 2013 at [www.eu-patient.eu](http://www.eu-patient.eu) [↑](#endnote-ref-27)
28. A useful definition of patient safety culture: “A safety culture is where staff within an organisation have a constant and active awareness of the potential for things to go wrong. Both the staff and the organisation are able to acknowledge mistakes, learn from them, and take action to put things right. To reduce the likelihood of incidents occurring, patient safety needs to be addressed at an institutional level, ‘from trust board to ward’, as well as by designing out errors in processes and equipment.”

    (Source:

    [www.nrls.npsa.nhs.uk/resources/patient-safety-topics/human-factors-patient-safety-culture/](http://www.nrls.npsa.nhs.uk/resources/patient-safety-topics/human-factors-patient-safety-culture/) ) [↑](#endnote-ref-28)