

EPF Position Paper on Quality of Care

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1. Introduction

Patient safety and quality of care have been a priority area for EPF since the founding of the organisation. Patients everywhere in the EU should have equitable access to healthcare that is of high quality. Already in 2008, EPF called on the European Commission for “an independent body responsible for setting and monitoring performance against safety standards, with a well-defined set of quality criteria standards and an ongoing monitoring approach”.

Our Strategic Goals, adopted in 2013 for the 2014-2020 Strategic Plan, explicitly link access and quality.

GOAL 2: Healthcare Access and Quality

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

[EPF Strategic Plan, 2014-2020](#)

As quality of care is now high on the policy agenda, prompted by concerns about health systems’ sustainability but also debates about access and patient-centredness, EPF wishes to bring the patient perspective to the ongoing debates. We started in 2015 by surveying patient representatives on what they think about quality in healthcare.¹

This position paper is largely based on the results of the survey as well as EPF’s other related work. This paper is not intended to be scientific, but rather to provide some insights into the priorities of patients and patient representatives, via consultation of EPF’s membership. The paper will provide insight and information to guide EPF’s future advocacy work.

Note: this paper does not concern itself with the *quality and safety of medicines or medical devices*, which are covered under specific other work by EPF. Whilst we do touch on *patient safety* given it is a core aspect of overall quality, we have dealt with patient safety extensively elsewhere and it will not be the focus of this position paper.

2. What is quality of care?

There are a great number of definitions of quality of care in healthcare. Two classic definitions are the **Avedis Donabedian** definition of the “kind of care which is expected to maximize an inclusive measure of patient welfare, after one has taken account of the balance of expected gains and losses that attend the process of care in all its parts,” and the **Institute of Medicine (IOM)** definition as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge”. Within various definitions, there is great variability as to the core aspects of “quality”.

¹ Medicine safety, and the safety of medical devices, is an important area of patient safety and quality of care, but it is outside the scope of the present report. For more information on these topics please see the relevant sections on EPF’s website.

There is a need for more systematic understanding about how patients define “quality”. This paper hopes to provide some answers, whilst making recommendations for further actions and study.

In this paper, we do not endorse any particular definition of quality; we also do not make a distinction between private and public healthcare provision. Nevertheless, we would welcome a common definition of quality that would apply to all EU Member States.

We do make reference to the *six dimensions* defined by the **World Health Organization** – effectiveness, efficiency, accessibility, acceptability/patient-centredness, equity, and safety. We also refer to the European Commission’s Expert Panel on Effective Ways of Investing In Health (EXPH), which in 2014 defined *five key dimensions* that all health care services should have regardless of the level of care: effectiveness, safety, appropriateness, patient-centredness, and efficiency/equity (though we note that the last dimension actually includes two separate dimensions).

The dimensions of quality as defined by the WHO vs. the EU EXPH

WHO	EU EXPH
<i>Effective</i> : Delivering health care that is adherent to an evidence base and results in improved health outcomes for individuals and communities, based on need.	<i>Effective</i> and improving health outcomes
	<i>Appropriate</i> and complying with current professional knowledge as well as meeting agreed standards
<i>Efficient</i> : Delivering health care in a manner which maximizes resource use and avoids waste.	<i>Efficient and equitable</i> and leading to the best value for the money spent and to equal access to available care for equal need, utilization and equal quality of care for all
<i>Equitable</i> : Delivering health care which does not vary in quality because of personal characteristics such as gender, race, ethnicity, geographical location, or socio-economic status.	
<i>Accessible</i> : Delivering health care that is timely, geographically reasonable, and provided in a setting where skills and resources are appropriate to medical need.	
<i>Acceptable/patient-centred</i> : Delivering health care which takes into account the preferences and aspirations of individual service users and the cultures of their communities.	<i>Patient-centred</i> and involving patients/people as key partners in the process of care
<i>Safe</i> : Delivering health care which minimizes risks and harm to service users	<i>Safe</i> and preventing avoidable harm related with care

Later in this paper, we will show how patients’ preferences compare to the two frameworks presented above.

3. Quality of care on the EU policy agenda

The legal framework on quality of healthcare (including patient safety) is restricted to specific areas by Article 168 of the Treaty on the Functioning of the European Union, which leaves the responsibility for organisation and delivery of healthcare to member states. Binding legislation – regulations and directives – to harmonise Member State laws is only possible in specific areas of exception. However, the EU can act to complement and support national policies in areas where Member States could not act effectively alone.

In the area of patient safety, the EU point of reference is the **2009 Council Recommendation**, which although not legally binding nevertheless carries quite a lot of political weight.² There was a gradual shift at European level towards addressing quality in a broader sense than only patient safety: the first steps on quality in its wider sense were taken in 2010, with meetings of the European Commission’s Working Group on Patient Safety which contributed to the publication of a reflection paper “Quality of Healthcare: Policy Actions at EU Level” (reflection paper no. 9366). This paper outlined specific objectives for improving the quality of healthcare in the EU and possible policy options to achieve these objectives. EPF contributed to the paper as a member of the Patient Safety WG.

Regrettably the Commission’s Working Group (later named Expert Group) has now been discontinued, and the role of patient safety and quality of care effectively downgraded in EU policy in the last years. However, health systems performance is among the explicit priorities assigned to the current European Commissioner for Health, and in 2015, the Expert Group on HSPA – consisting of Member States only – identified quality of care as a topic of importance.³ The EU also supports the collection of healthcare quality indicators by the OECD, which form part of the EU health statistics.

Action at European level focuses on voluntary collaboration and exchange of best practice. However, the **EU Directive on the application of patients’ rights in cross-border healthcare** (Directive 2011/24/EU)⁴ contains some important provisions that have implications for the safety and quality of care: it requires Member States to provide cross-border healthcare in accordance with applicable safety and quality standards and guidelines, to provide information to patients on those standards and guidelines, and to collaborate with each other on the development of these. For more information, please refer to EPF’s extensive policy work on cross-border healthcare, available on our website.⁵

3.1 PAST PROJECTS

Projects on patient safety have been funded under the EU Health Programme for a decade or so. Notably, the **EUNetPaS** project (2008-2010) had established patient safety platforms in several Member States and led to a Joint Action, which started in 2012. Since 2010, however, there has been a shift in EU policy towards addressing quality in a broader sense at European level, rather than focusing on patient safety as a distinct area, as was the case before. This has been increasingly

² For more on the legal framework, see EPF Briefing Paper on Patient Safety (2015)

³ So what? Strategies across Europe to assess quality of care. Report by the Expert Group on Health Systems Performance Assessment 2016. Available at https://ec.europa.eu/health/sites/health/files/systems_performance_assessment_docs/sowhat_en.pdf

⁴ <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:088:0045:0065:en:PDF>. The Directive draws on a double legal basis: Art. 168 TFEU on Public Health and Art. 114 TFEU on the Internal Market.

⁵ For example, the EPF guidance document for patient organisations (2012), position paper (2015) and reports from our series of regional conferences, available at <http://www.eu-patient.eu/whatwedo/Policy/Patients-Mobility/>

accepted by Member States and its priority was confirmed by the responses from stakeholders to the public consultation performed as part of the release of the European Commission's "*Patient safety package*" in 2014.

The ***European Union Network on Patient Safety and Quality of Care (PaSQ)*** was a Joint Action in which EPF was an associate partner representing patients. The Joint Action ran from April 2012 until March 2016. Its objectives were to support Member States in the implementation of the Council Recommendation on patient safety and initiate co-operation between Member States on quality of healthcare. PaSQ served to further strengthen co-operation between EU Member States, international organisations and EU stakeholders on issues related to quality of healthcare, including patient safety. The Joint Action mapped and identified existing good practices in patient safety and quality of care from across the EU, analysed them and supported the implementation of a selection of evidence-based good clinical practices in certain Member States.⁶

3.2 EPF'S WORK ON QUALITY OF CARE

EPF is highly active in the area of quality of care. In addition to the contributions mentioned above, through the European Commission's now-discontinued Expert Group, the EUNetPaS project and the PaSQ Joint Action, we have worked closely with international organisations and stakeholders on patient safety-related topics.

EPF has long advocated for the vital importance of the patients' perspective in defining quality. In 2010, EPF contributed to the draft Commission reflection paper "*Quality of healthcare: policy actions at EU level*", which emphasised the importance of patient-centred healthcare and recognised patient involvement as a cross-cutting theme with relevance to most elements of healthcare quality.⁷ In February 2014 EPF responded to the *public consultation* launched by DG Sante (then SANCO) to call for more collaborative work on quality and safety of healthcare.

EPF has also collaborated with the *WHO Regional Office for Europe*, in our role as the EU-level umbrella patient organisation, in the area of patient safety. In 2007, we reviewed the document "National health system quality and safety strategies: guidance for WHO Europe member states", stressing the importance of the need to provide adequate resources for patient organisations in order to enable them to participate in a meaningful way in safety and quality interventions. In 2010, we participated in the initiative "Patient safety and patients' rights", which explored linkages between patient safety and patients' rights, and particularly the possibilities to improve patient safety by enhancing patient empowerment and health literacy. EPF contributed in a workshop and reviewed the report resulting from this project, which was published by WHO in 2013.⁸

More recently, EPF participates in the OECD PaRIS initiative, launched in January 2017 in order to assess health system performance from the patient's perspective. The aim of PaRIS is to develop internationally comparable server instruments to collect data patient reported health outcomes (PROMs) and patients' experience of care (PREMs). This data should ultimately support health systems to become more knowledge-based and person-centred; to achieve better governance, particularly by

⁶ See the Joint Action website: www.pasq.eu

⁷ Commission draft reflection paper no. 9366/10, page 7 (March 2010)

⁸ Exploring patient participation in reducing health-care-related safety risks. Available at www.euro.who.int/_data/assets/pdf_file/0010/185779/e96814.pdf

reducing waste; to understand and plan for complex care needs; and to understand and manage new technological developments, such as personalised medicine.

4. The role of patients in improving quality

Patients are by necessity frequent and long-term users of healthcare (and social care) services. Patients depend more than other people on the quality and accessibility of such services. For this reason, their perception of healthcare, experience of the care process, and evaluation of various indicators may be different from that of the general population.

Patient-centeredness is today recognised as a core component of quality care. Patient-centred care models have been shown to be cost-effective and improve outcomes: when patients are genuinely involved in healthcare decisions and their preferences are listened to and acted on, the result is better health, more engaged patients and lower costs.⁹ Increasingly, patients are seen as “co-producers” of health or well-being.¹⁰

The Third EU Health Programme recognises this: Regulation (EU) No 282/2014, recital 12 states that “[t]he transparency of healthcare activities and systems and the availability of reliable, independent and user-friendly information to patients should be optimised. Healthcare practices should be informed by feedback from, and communication with, patients.” The European Commission’s second implementation report on patient safety (2014) referred to the *experiential knowledge* of patients and families as a valuable resource for health professionals, and recommended that it should be gathered as an element of quality improvement systems.¹¹ Patients’ involvement is also vital for instilling a patient safety culture in the healthcare system.¹²

Despite the accumulating knowledge and evidence-base, however, “patient-centredness” is not clearly defined in the quality field, and the value of patient involvement is not universally recognised. Knowledge about methodologies and good practices for ensuring systematic, structured and meaningful patient enrolment in different areas and levels of the healthcare system is also lacking.

With the recent OECD PaRIS initiative, the patient experience is now formally being recognised as a key evaluation tool in assessing the quality of healthcare and health systems’ performance overall. This is good news, but it requires careful implementation of meaningful patient involvement throughout.

5. Patients’ perceptions of “quality” based on our survey

Based on the responses to the EPF survey, patients tend to perceive quality of healthcare both in terms of their personal experiences and in terms of the national healthcare system and public health more broadly. Healthcare provided in non-medical environments, such as care homes and at home are also

⁹ Mulley et al, 2012; Arterburn et al 2012; Veroff et al, 2013.

¹⁰ The Health Foundation 2013, Mulley et al., 2012; Reflection Process on Chronic Diseases, Final Report, 8 October 2013.

¹¹ EPF’s concept of meaningful patient involvement, formulated already in 2009 in the Value+ project, is based on this premise: “Patients [should be enabled to] *take an active role in activities or decisions that will have consequences for the patient community*, because of [the intrinsic value of] their *specific knowledge and relevant experience as patients*.” (EPF project “VALUE+”, 2009).

¹² Reports of sub-groups of the PSQC WG on education in patient safety and reporting-learning systems, April 2014. Available at http://ec.europa.eu/health/patient_safety/policy/package_en.htm

relevant, since many patients live and age with multiple chronic conditions and self-care constitutes a large part of what patients do to manage daily life. The provision of assistive devices such as wheelchairs and mobility supports is also considered part of care – thus “healthcare” for patients is not necessarily confined within the healthcare provision strictly speaking, but also links very closely to social care provision.

Recurrent priorities mentioned by patients include paying attention to mental as well as physical health; well-trained healthcare professionals; a partnership approach; supporting patients’ health literacy and capacity to manage everyday life with illness. References were also made to human and patients’ rights; and issues relating to access, such as the right to a second opinion, the role of complementary therapies, and being able to choose a public or private provider with no cost implication. The role of prevention, rehabilitation and other non-medical services was also considered important. Respondents also mentioned the importance of community involvement and that the different areas of the system should be working in tandem. The importance of outcomes was stressed, because a healthcare system that does not deliver meaningful outcomes implies a waste of resources.

Diagnosis is considered an important part of healthcare. Our survey showed that accurate and timely diagnosis is a key priority during the patient’s “journey”.

Quality of life is a huge priority: patient say that receiving “good” medical treatment means that they are able to live well even though having a chronic condition; feeling well-treated also helps minimise the negative emotional and social impacts of having a disease or condition.

Patients have a strong wish for **better communication, more information**, and a **more genuine partnership** with the healthcare professionals. They are usually willing to take on a more active role in their care – and ask also for a greater recognition of all the self-care and self-management that they already do.¹³

Patients’ concept of quality includes both more objective and relational or “human” aspects, and is often also aspirational towards **universal access**; affordability or low/no-cost treatment was highlighted many times in responses to our survey.

Patients appreciate very well the need to use limited healthcare resources rationally. However, sometimes they regard the **efficiency** aspect with some suspicion: some feel that promotion of efficiency and avoiding waste as a priority may result in insufficient resources being allocated to healthcare, particularly in terms of numbers of healthcare professionals, which can lead to overwork, burnout and have a negative impact on access to as well as the quality of care. It is also commented that the efficiency discourse may be overly focused on pharmacological treatment, with therapies, peer support/self-help groups and other such supports being easily considered as “less efficient” uses of resources.

Regarding **safety**, very few comments were received. First, it should be borne in mind that no effective treatment can be said to be entirely devoid of risk, and therefore patients appreciate that safety of

¹³ This is consistent with the findings of the Eurobarometer Qualitative Study on Patient Involvement in Healthcare (2012), which showed that patients with chronic diseases are more critical of health services than other people but also more willing to become active in their own care and in improving quality for others.
https://ec.europa.eu/eip/ageing/library/eurobarometer-qualitative-study-patient-involvement-healthcare_en

treatments involves balancing potential benefits versus risks (especially so with regard to medicines). Patients point out that “sometimes risky treatments are necessary”. One commentator stressed the importance of defining what outcomes are desired, saying that “I don't mind m

y chemotherapy being aggressive, as long as it kills the cancer cells.” Another explanation for the lack of comments received on safety could be that patients take general patient safety – e.g. in the hospital or primary care environment – for granted and something they should not have to worry about. Based on EPF feedback patients also sometimes do not see safety as a serious concern if they have not experienced medical error or other adverse incident, either themselves or through someone close to them.

In our survey, we attempted to achieve a prioritisation between different aspects of quality, but the responses were somewhat contradictory and ultimately inconclusive. Several respondents said it was not useful to try and “rank” aspects of quality, because they are all important. Moreover, the patient’s priorities may be different at each interaction with the healthcare system. The only fairly consistent response was that the aesthetics of the healthcare environment were not considered important. As one respondent put it:

“There is no point in having effective/latest treatment if no-one can afford it but equally, without correct diagnoses, people die... Also, without including the patient, i.e. listening to them, the treatment cannot be effective... and although listed lower on my list (something has to be), if the communication skills are not there, the patient isn't being listened to, things are being missed, the patient isn't adhering to medication regimes and so on. I have listed latest treatments quite low down on the list simply because some people would be happy to have any kind of treatment first of all, but it is no less important.”

Main aspects of quality as defined by patients, mapped on to the WHO/EXPH domains

WHO	EU EXPH	PATIENTS
<p>Effective Delivering health care that is adherent to an evidence base and results in improved health outcomes for individuals and communities, based on need.</p>	<p>Effective and improving health outcomes</p>	<p>Effective and up-to-date</p> <ul style="list-style-type: none"> Best achievable health outcomes; latest interventions based on latest scientific evidence and best practices; following clinical guidelines; well-trained professionals <p>“Quality of life as priority outcome</p> <ul style="list-style-type: none"> Health outcomes but also others, such as being able to keep active, able live as normally as possible; quality of life according to patient, not generic “scorecard.”
	<p>Appropriate and complying with current professional knowledge as well as meeting agreed standards</p>	
<p>Efficient Delivering health care in a manner which maximizes resource use and avoids waste.</p>	<p>Efficient and equitable and leading to the best value for the money spent and to equal access to available care for equal need, utilization and equal quality of care for all</p>	<p>Equitable</p> <ul style="list-style-type: none"> Access for everyone who needs it according to needs, not means; free (public) healthcare; patients needing to worry about affording care or having catastrophic financial impact as a result of being ill Equal access and treatment regardless of patient’s background or situation
<p>Equitable Delivering health care which does not vary in quality because of personal characteristics such as gender, race, ethnicity, geographical location, or socio-economic status.</p>		
<p>Accessible Delivering health care that is timely, geographically reasonable, and provided in a setting where skills and resources are appropriate to medical need.</p>		<p>Accessible</p> <ul style="list-style-type: none"> Timely and accurate diagnosis with prompt follow-up treatment; not having to wait too long for either diagnosis or treatment
<p>Acceptable/patient-centred Delivering health care which takes into account the preferences and aspirations of individual service users and the cultures of their communities.</p>	<p>Patient-centred and involving patients/people as key partners in the process of care</p>	<p>Tailored</p> <ul style="list-style-type: none"> Adapted to individual needs and preferences First question is he “What matters to you?” <p>Collaborative</p> <ul style="list-style-type: none"> Patient and professional find solutions together; professional takes time to listen, helps patient decide; being offered alternative options and deciding together.
<p>Safe Delivering health care which minimizes risks and harm to service users</p>	<p>Safe and preventing avoidable harm related with care</p>	<p>Trust in the safety and quality of care</p>

Other aspects identified by patients not covered by WHO or EXPH

<p>The human face</p> <ul style="list-style-type: none"> • Being cared for as a whole, as a person with context, not being treated as a diagnosis or a number, attention paid to psycho-social, mental and family aspects of illness together with physical aspects. • Empathy – professionals are able to put themselves in the patient’s shoes 	<p>Communication and dialogue</p> <ul style="list-style-type: none"> • Medical professionals communicate their reasoning and make patients understand; shared decision-making as standard practice; checking patient’s understanding of what has been discussed and agreed, and a meaningful informed decision by patient; enough time to talk and reflect • Information to complement person-to-person encounter, provided in patient/lay-friendly language, format, presentation and easily accessible when you need it. 	<p>Improvement and learning culture</p> <ul style="list-style-type: none"> • Learns from the past to see if anything could be done better for other patients; involves patients in feedback and improvement loop
<p>Enabling and preventative</p> <ul style="list-style-type: none"> • Guides the patient and minimises hassle with bureaucracy; being helped in a way that you yourself are actively involved; being accepted and welcomed as equal partner; family involvement especially if patient is in a vulnerable position • Having enough and the right support for effective self-care • Aiming to prevent further suffering and exacerbations 	<p>Integrated and co-ordinated</p> <ul style="list-style-type: none"> • Understanding patient’s situation, impact of the disease and social circumstances • Having the same doctor/other HCP who knows your history; knowing who is responsible for you • Multi-disciplinary teams organised around patient’s /family’s needs, taking a holistic approach, i.e. also non-medical needs 	<p>Trust and respect</p> <ul style="list-style-type: none"> • Feeling that if one is in competent hands; relationship of trust with the professionals involved in your care • Being listened to and taken seriously; respect for the patient’s choices; belief in patient’s observations; taking patient seriously.

6. Information for patients on the quality of healthcare

Information and health literacy form such an important aspect of patients' empowerment and involvement that these topics must be highlighted as aspects of quality in healthcare.

According to our survey, patients tend to get information on quality mostly from medical professionals and from patient organisations. Hospitals and "Dr Google" are also very common sources, as are friends and family. However, patients do not favour commercial companies for information of this kind.

6.1 QUALITY OF INFORMATION

Information on quality and safety is often difficult to understand for a lay patient. The criteria and indicators used vary widely. There is often too much information, or information on aspects that are not relevant for patients. At the same time, there is also a lot of incorrect or false information available, and it is not easy for patients to always gauge the level of reliability, especially for people with low health literacy. We strongly believe there is a need for better, more patient-oriented information by trusted (public) institutions.

Under Directive 24/2011, Member States must provide information for patients on the quality and safety standards for healthcare providers applied in the country, including provisions for the supervision and assessment of healthcare providers ("fitness to practice") and which providers are subject to those standards and (as some standards may only apply to public or only private healthcare providers). Information about specific providers' status only needs to be provided on request. The information should enable patients to make an informed choice. (Art 4(2)b). National Contact Points who created for the purpose of informing patients and the public.¹⁴

Currently, this aspect of the Directive has been poorly implemented across the EU. The information that is available through National Contact Points is inconsistent. A 2015 Commission evaluative study showed "only a few websites published practical and easily understandable information ... to help patients make an informed choice."¹⁵ The EU study further notes that "no universal definition of 'quality standards' currently exists across Member States. Although it is, admittedly, quite challenging to agree upon such a definition, the patient community would warmly welcome such a development. At the same time, developing disease-specific definitions would be a more pragmatic and still useful step forward.

¹⁴ Healthcare providers (i.e. those that wish to provide services for cross-border patients) must also give patients information that enables an informed choice, including treatment options and their availability; the quality and safety of the healthcare provided; information about their authorisation status and professional liability provisions.

¹⁵ http://ec.europa.eu/health/cross_border_care/docs/2015_evaluative_study_frep_en.pdf

6.2 HEALTH LITERACY

Information in itself is important, but not enough. **Health literacy** refers to people's knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.¹⁶ Health literacy is a key dimension of patient empowerment, and highly relevant to patient safety and quality.¹⁷ Low health literacy is associated with reduced use of preventive services and management of chronic conditions, and higher mortality.¹⁸ It is associated with medication errors, misdiagnosis due to poor communication between providers and patients, low rates of treatment adherence, hospital readmissions, and other related complications.¹⁹

Health literacy supports patients in becoming aware of their experience and role, further channelling their input into the daily experience, such as participating in *shared decision-making* concerning treatment.²⁰ It is not only about patients as recipients of information, but also about patients finding the confidence and the language which allows them to participate in the care process to the extent that they wish to do so. It is telling that many patients express a strong wish for more information, full and clear explanations.

7. Key Recommendations

The recommendations below are based on the EPF survey followed by consultation with EPF's membership. They are grouped in several priority areas as identified by patients.

Patient involvement

- Meaningful, systematic, unstructured patient involvement in quality improvement and in healthcare care at all levels needs to become a reality and part of a shift towards a patient/person-centred healthcare approach.
- Patients are often referred to as “the most underused resource” in healthcare, and they should be recognised as vital partners in improving quality and efficiency.
- Patient organisations play an important role in awareness raising and capacity building around safety and quality. They should be supported in this role by providing them with adequate resources, including core funding ideally in a transparent, diversified mix of public and private funds.

Assessment of the quality of care – health systems' performance

¹⁶ Sorensen K et al., Health literacy and public health: A systematic review and integration of definitions and models BMC Public Health. 2012

¹⁷ See EPF briefing paper (2014) available at www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/Background-papers/

¹⁸ Berkman ND et al., Literacy and Health Outcomes; AHRQ; Rockville, MD, 2004

¹⁹ Nielsen-Bohlman L, Panzer AM, Kindig DA (2004), A Prescription to End Confusion. Project brief; Vernon JA, Trujillo A, Rosenbaum S, DeBuono B (2007). Low health literacy: Implications for national policy.

http://publichealth.gwu.edu/departments/healthpolicy/CHPR/downloads/LowHealthLiteracyReport10_4_07.pdf

²⁰ “a collaborative process that allows patients and their providers to make healthcare decisions together, taking into account the best scientific evidence available, as well as the patient's values and preferences.” Informed Medical Decisions Foundation, <http://www.informedmedicaldecisions.org/what-is-shared-decision-making/>

- Health system performance assessment should focus on outcomes – but those that matter to patients.
- A common European definition of “quality of care”, based on those aspects that patients find most important, should be developed for use in assessment and benchmarking.
- Key indicators for assessing healthcare quality should be defined by patients themselves, and not by what providers assume is important for patients.
- Patients’ feedback, our feedback, should be encouraged, listened to, and acted upon. This should not be interpreted as a doing using “patient satisfaction surveys”, which can easily become a mere tick-box exercises that fails to capture the real picture of the patient’s experience and the real value of their insights. Incorporating meaningful measures – including qualitative information – for outcomes and processes will be key to success.

Health literacy and information

- Patients should always be given copies of their own medical information, including reports of scans and pathology reports, lab results and so on.
- Information for patients must be simple, relevant and concise, addressing patients’ priorities. It should be provided in a format that is accessible for persons with disabilities and easily understandable to lay persons. It should adhere to the European “core quality principles for information to patients.”
- Information on quality should be comparable across healthcare providers within one country but also across health systems across EU Member States.
- An “at a glance” resource at national level to check qualifications and fitness to practice of healthcare professionals and providers and would be useful and could eventually be combined into a “one-stop” EU level portal.
- Development of guidelines on which “core” information on quality of care should be provided to patients by member states, and how it should be presented, with recommendations on good practice such as health literacy principles; this should be co-produced with patient organisations.
- Guidance for patients on how to interpret safety and quality information, including lay-friendly explanation of key concepts, should be developed in a collaboration between patient organisations and safety/quality experts.
- Member States should collaborate at European level to encourage comparability and general upward convergence of national safety and quality standards, for example through benchmarking and key indicators.

Communication – health workforce skills

- Communication skills, especially skills to involve and empower patients, such as active listening, health literacy principles and using lay language, must become a priority in healthcare professionals’ training and continuing professional development.
- Ways need to be found to give more time to patient-professional interactions.
- Adequate staffing and avoiding all the work is vital for patient safety and quality, to avoid staff that is stressed, burned-out and thus not only vulnerable to errors but also is capable of being patient-centred.

Transparency of the healthcare system

- Healthcare systems should be more transparent on how they spend public money, and on prioritisation criteria including how unmet needs are taken into account and what considerations are given to cost-effectiveness.
- Authorities should be transparent on decisions around pricing and reimbursement of treatments, including but not only medicines, and on what criteria these decisions are taken.

Access and affordability

- Efforts must be made to shorten waiting times, starting from access to accurate diagnosis and including primary care as well as specialist consultations and in-patient procedures.
- Affordability of and access to healthcare for patients must be a priority; Member States should implement the recommendations of the *EPF Roadmap on Access*, which sets out concrete steps to improve access for all patients according to the UN sustainable development goals by 2030.

Integration of care

- Integration of care should be a priority for policymakers and practitioners. Integration should be both vertical – between levels of care from specialist to primary/community care – and horizontal – between health and related, e.g. social care. It should be “well co-ordinated” and smooth from the perspective of the patient and their family, and co-designed with them.

Strengthening the role of patients and patient organisations

- Healthcare professionals should refer patients to patient organisations in their relevant disease-area or locality/region, to provide an easy path towards peer support and information.
- Patient organisations should be appropriately and sustainably resourced at all levels, from European to national and local, and engaged as active and full partners in quality improvement and monitoring efforts.

8. Conclusion

A more proactive role adopted by empowered patients in their health and in improving the quality of healthcare, as well as in health policy more broadly is key to ensuring the high quality of our future health systems and addressing the challenges of chronic diseases, constraints on health budgets and rapid developments in technology, whilst advancing the concept of patients as partners in co-producers of well-being. Meaningful, systematic and structured patient involvement is vital to making this happen.

Equipping patients with the capacity to take an active part, and creating an enabling environment for this to happen – *patient empowerment* – requires committed efforts and a change in attitudes:

- from health professionals regarding the “proper role” of patients;
- from policy-makers, a recognition of the added value brought by the patient perspective

Health professionals need to be trained to be more aware of the needs of their patients, including communication and giving information, paying attention to bearing health literacy levels, and the

positive attitude towards patient involvement must be instilled in professional training. These measures are part of building a patient-centred culture focused on continuous improvement. It is also crucial to empower patients in all aspects of health and care through high-quality information and by building health literacy.

EPF calls policymakers and practitioners alike to recognise the essential role of patients as an “untapped resource” in improving the quality of healthcare and take the lead in following up on the relevant recommendations as they apply to different stakeholder groups. The European Patients’ Forum and its members across the EU are committed to partnering with others who wish to lead change in this important area.



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