

“Patients’ Perceptions of Quality in Healthcare”

Report of a survey conducted by EPF in 2016

February 2017



Contents

1. Introduction.....	3
1.1 Addressing quality of care at European level.....	4
1.2 The role of patients	6
2. Methodology of the EPF survey	7
3. Results.....	7
3.1 General information.....	7
3.2 Putting quality of healthcare in context	10
3.3 Patients’ descriptions of “high-quality healthcare”	13
3.4 What is most important to patients?.....	18
3.4.1 Rating of Different Aspects of Quality	18
3.4.2 Top six dimensions of quality.....	20
3.4.3 Perceptions of the 6 dimensions of quality in the WHO definition.....	21
3.5 Where do patients get information on quality of healthcare?.....	24
3.6 Views on healthcare quality offered	25
3.7 What needs to change	25
4. Discussion	30
5. Conclusions and recommendations	31
6. Annex: Survey questionnaire.....	34

1. Introduction

A more proactive role adopted by empowered patients in their health and in health policy 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 “co-producers” of health. (The Health Foundation 2013, Mulley et al., 2012; Reflection Process on Chronic Diseases, Final Report, 8 October 2013) The Third Health Programme recognises this and 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. Healthcare practices should be informed by feedback from, and communication with, patients.” (Regulation (EU) No 282/2014, recital 12)

Health systems performance is among Commissioner Andriukaitis’s stated priorities; quality of care and integrated care were identified by member states as priority topics for the Expert Group on HSPA in 2015-16.

Patient-centeredness is recognised as a core component of quality care. (EXPH, 2014) 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. (Mulley et al, 2012; Arterburn et al 2012; Veroff et al, 2013)

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 that it should be gathered as an element of quality improvement systems. Patients’ involvement is also vital for instilling a patient safety culture in the healthcare system.¹ Nevertheless, at the moment patient-centredness is a little developed area of quality, and patient involvement is not universally recognised.

EPF wishes to bring the patient perspective to the ongoing debates on health systems performance and quality of care. We decided to start by serving patient representatives on what they think about quality in healthcare.² EPF developed the survey in 2015 to launch in 2016. It aims to explore the key dimensions of quality identified in literature from a patient perspective, with the aim of contributing to EPF’s future policy recommendations on quality of care.

¹ 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

² 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.

Patient safety and quality of care have been a priority area for EPF since the founding of our organisation. This is reflected in our Strategic Goals, of which Goal No. 2 explicitly links 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](#)

1.1 ADDRESSING QUALITY OF CARE AT EUROPEAN LEVEL

The legal framework on quality of healthcare (including 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.³

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 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 EU joint action on patient safety and quality of health care (PASQ)

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

³ For more on the legal framework, see EPF Briefing Paper on Patient Safety (2015)

from across the EU, analysed them and supported the implementation of a selection of evidence-based good clinical practices in certain Member States.⁴

The directive on patients' rights in cross-border healthcare

The most recent binding legislation that touches on quality of healthcare⁵ is the *EU Directive on the application of patients' rights in cross-border healthcare* (Directive 2011/24/EU).⁶ The Directive draws on a double legal basis: Art. 168 TFEU on Public Health and Art. 114 TFEU on the Internal Market. It contains important provisions concerning safety and quality of care. For example, 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.⁷

EPF's work on quality of care

As mentioned in the introduction, patient safety is a core priority for EPF and we are highly active in this field. In addition to the contributions mentioned above, through the European Commission's Expert Group, EUNetPaS and PaSQ, 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.⁸ 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 2013.⁹

⁴ See the Joint Action website: www.pasq.eu

⁵ Apart, as stated, from the legislation regulating pharmaceuticals, medical devices and clinical trials.

⁶ <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:088:0045:0065:en:PDF>

⁷ 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/>

⁸ Commission draft reflection paper no. 9366/10, page 7 (March 2010)

⁹ Exploring patient participation in reducing health-care-related safety risks. Available at www.euro.who.int/_data/assets/pdf_file/0010/185779/e96814.pdf

1.2 THE ROLE OF PATIENTS

EPF would like to see patient organisations take a more active stance on patient safety and quality of care at policy level. Patients play a vital role in the management of chronic conditions. They live with their condition every day and become experts through lived experience, on the condition itself and its impact on their life, the impact of treatments, and the positive aspects as well as failures of the healthcare system which they rely on a regular basis. Nevertheless, we acknowledge the challenges related to individual patients' involvement in this area and the need for empowerment.

Supporting and promoting the **meaningful involvement of patients**, both individually and collectively in improving patient safety, is one of the priorities for EPF. "Meaningful patient involvement" as defined by EPF¹⁰ is based on the premise that patients have a *specific expertise* derived from lived experience – simply from being patients, which is a valuable source of *experiential knowledge*. The patient's perspective is not the same as the lay/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.

At *collective level*, patient organisations play a role in informing and educating the patient community as well as conveying patient feedback to health professionals. They are effective at advocacy, with direct and regular contacts with their grass-roots community. Through channelling their members' direct experiences, patient organisations are able to represent their views and concerns at health policy level, ensuring that health services are developed with the patient at the centre and that they meet the patients' real needs and preferences.

Through advocacy and participation in health policy making, patients and patient organisations can be involved in shaping healthcare systems to be more patient friendly and empowering to patients.

At *individual level*, patients can contribute by getting actively involved in their care. Their experience of their healthcare journey is a rich resource of information and learnings about gaps and failures in the system and can function as a "last safety barrier". Patients observe much during their journey; health professionals should take this seriously, give patients opportunities to speak, listen to what they have to say, and take action.

¹⁰ "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).

2. Methodology of the EPF survey

In order to develop the survey questionnaire, the EPF Secretariat undertook background research on quality of care and drafted an initial set of questions. We then asked the EPF Policy Advisory Group (PAG) to give feedback on the structure and content of the questionnaire and to identify additional questions. Their input helped shape the questionnaire.

The survey was then tested and conducted online through Survey Monkey. It ran from 24 February 2016 until 30 September 2016, a period of some six months.

This survey is not intended to be scientific, but rather to provide some insights into the perceptions of patients and patient representatives, mostly but not exclusively, from within EPF membership in order to provide guidance and inform EPF’s future advocacy work.

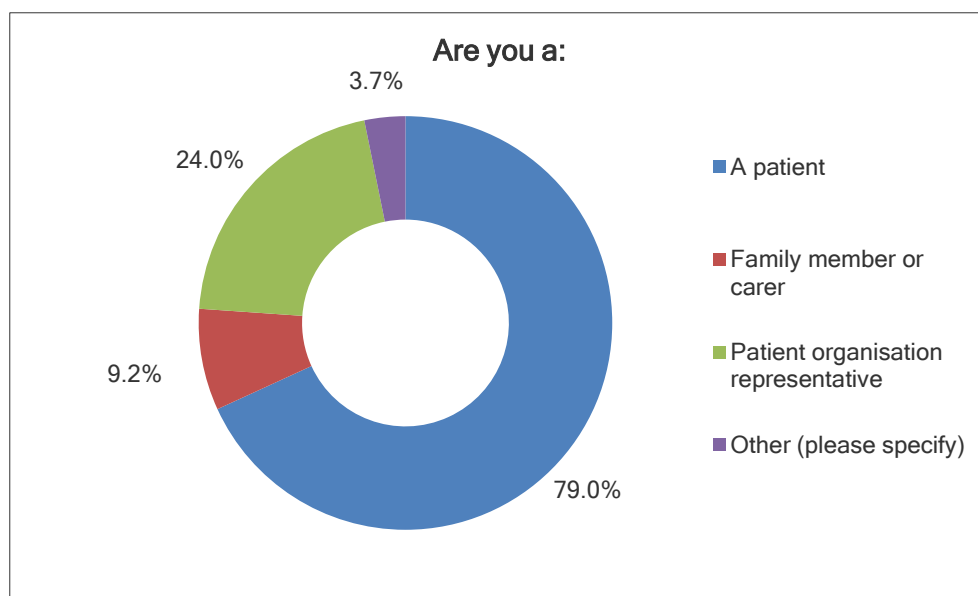
3. Results

A total of 678 responses were received, but less than half of those – 271 – answered all the questions. Below, we present the data based only on the complete responses.

3.1 GENERAL INFORMATION

Of the respondents, 214 (79%) identified themselves as patient, 65 (24%) as representative of a patient organisation, and 25 (9%) as family member or informal carer. Others, 10 (4%) included researchers, physician, hospital management, and people affiliated with support groups.

Chart 1: respondent identification (n= 271)



Respondents were mostly of working age: only seven respondents (2.5%) were under 21. Sixty-seven respondents (24.7%) were aged 30-49, 58 (21%) aged 50-59 and a similar proportion over 60. A significant majority of the respondents were women (71%).

Chart 2: Age distribution (n=271)

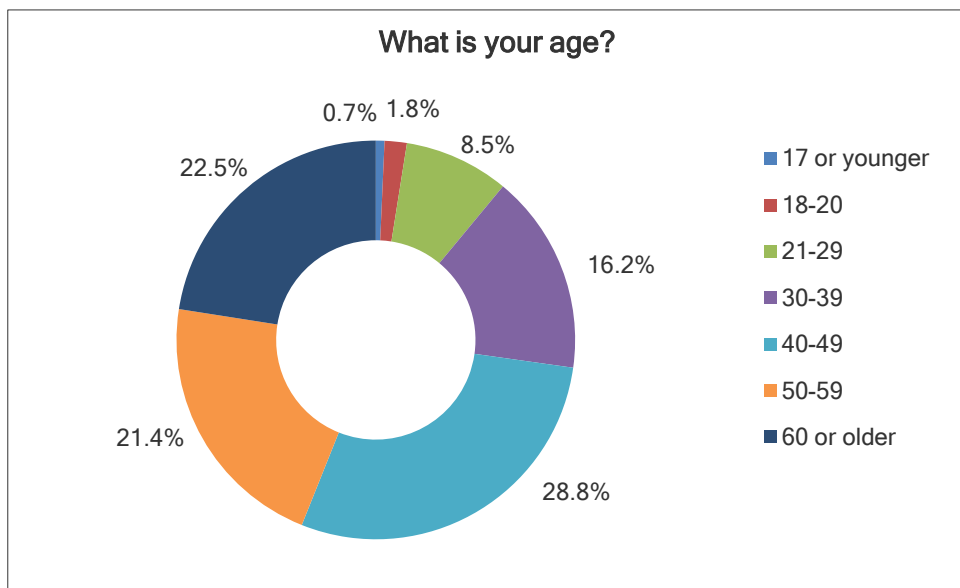
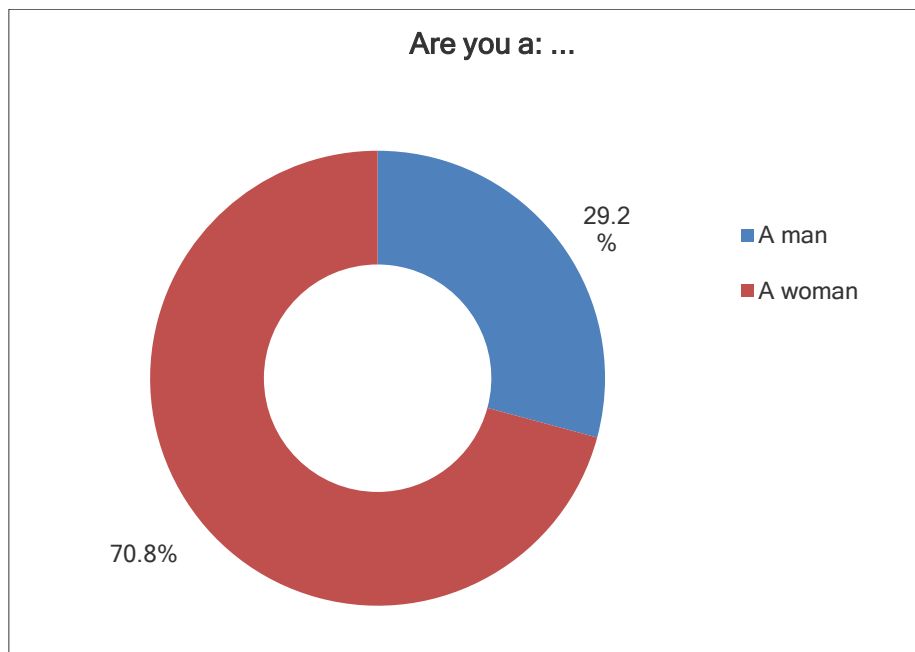


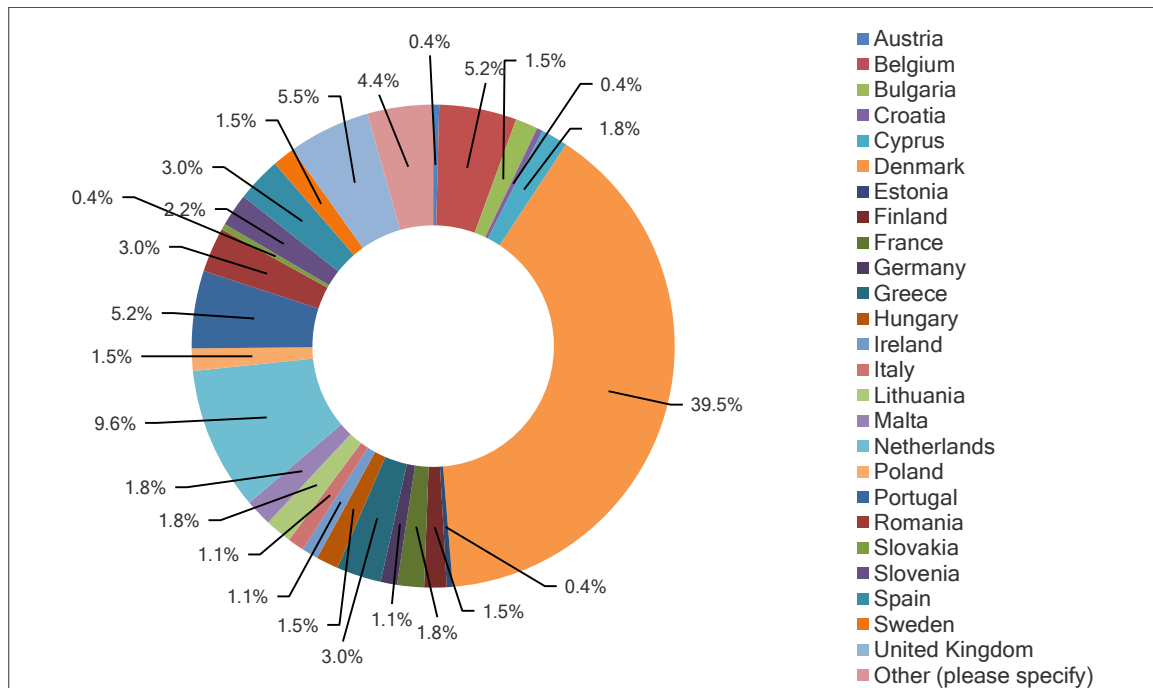
Chart 3: Gender distribution (n=271)



A large number of responses (107, or 36%) were received from Denmark. The reason for this is not known. Twenty-six responses, or just under 10% came from the Netherlands; 15 (5.5%) from the United Kingdom; 14 (5%) from Belgium and Portugal; 8 (3%) from Greece, Romania and Spain; six (2%) from Slovenia; and five (just under 2%) from Cyprus, France, Lithuania and Malta. A smaller number of responses – between two and five – were received from Bulgaria, Finland, Hungary, Ireland, Italy, Poland and Sweden.

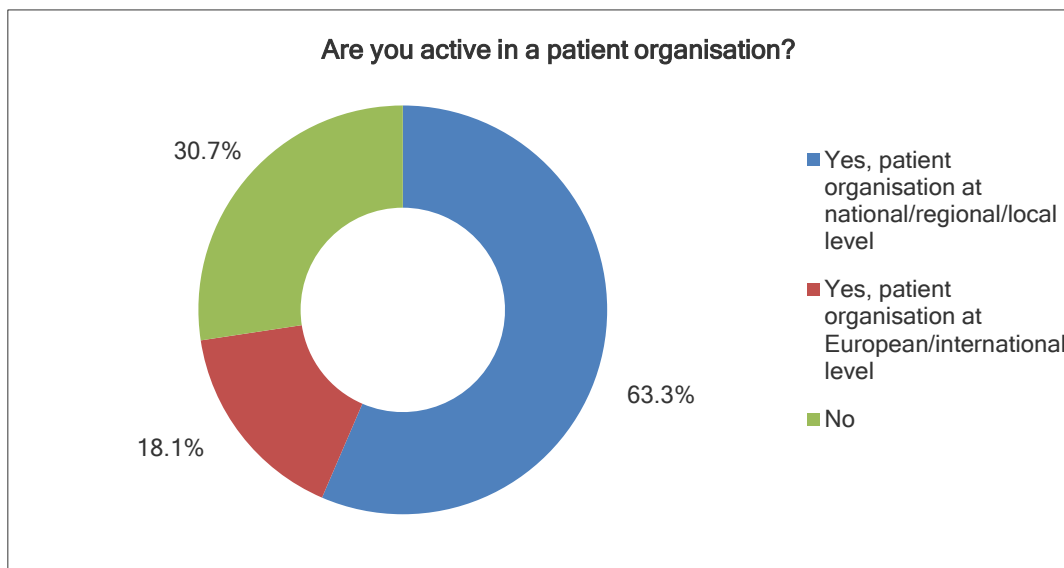
Single responses were received from Austria, Croatia, Estonia and Slovakia. No responses were received from the Czech Republic, Latvia and Luxembourg. In addition, 12 responses were received from “other” countries. These included: Switzerland (2), Macedonia (2), Russian Federation, Iceland, Norway (2), Serbia, Georgia and Turkey.

Chart 4: Country distribution (n= 270)



The great majority of respondents, namely 220 (81%) said they were active in a patient organisation. Of those, 171 (63%) were active at the national or local level, and 49 (18%) in a European or international organisation. However, 83 respondents (31%) said they were not active in any patient organisation.

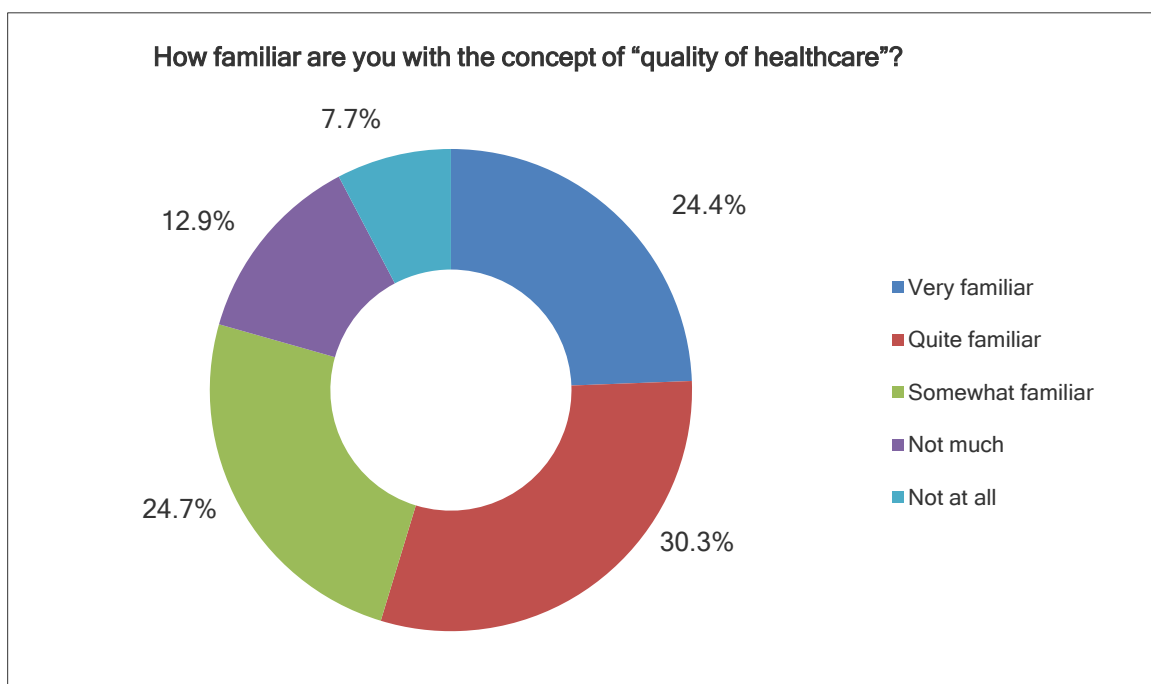
Chart 5: Patient organisation affiliation (n= 270)



3.2 PUTTING QUALITY OF HEALTHCARE IN CONTEXT

In the first part of our questionnaire, we asked how familiar the respondents were with the concept of “quality of healthcare”. The answers here were fairly evenly distributed with 24% consider themselves as being very familiar, 30% quite familiar, and 25% somewhat familiar. Only 13% said they were “not much” familiar and 8% “not at all” familiar with the concept.

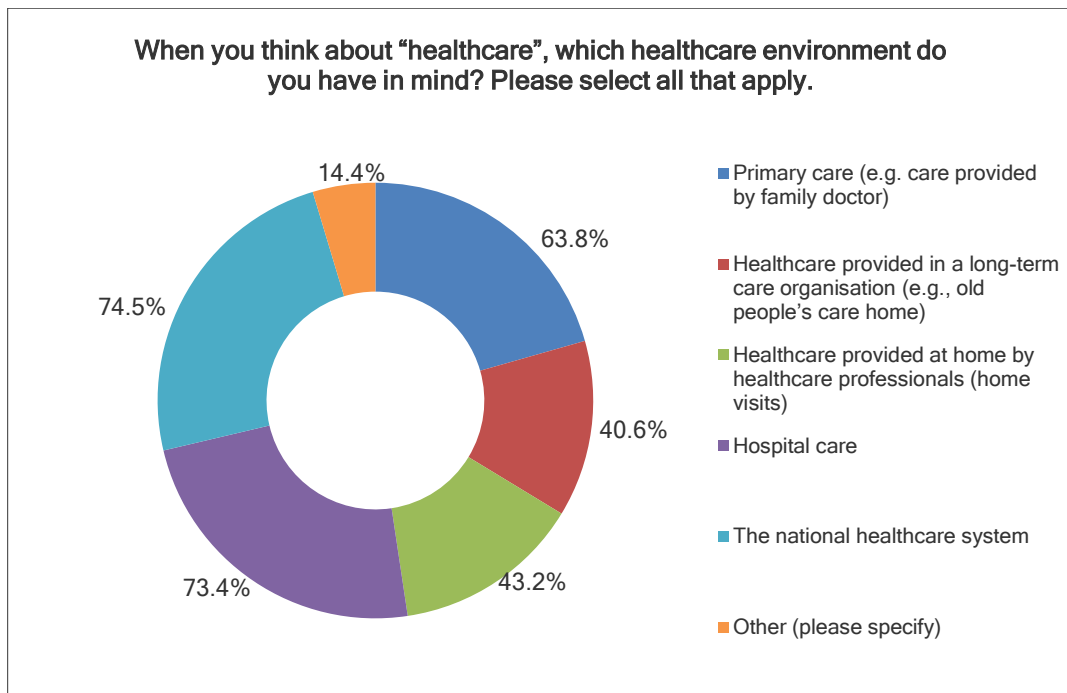
Chart 6: Familiarity with the concept of quality (n= 271)



Respondents were also asked to tell us what kind of healthcare environment they had in mind when they were answering the questions, since the idea of quality may have different meanings and implications depending on what healthcare environment the patient is thinking of.

Note: Respondents were able to take more than one option, thus the sum total of the answers is over 100%.

Chart 7: healthcare environment question (n= 271)



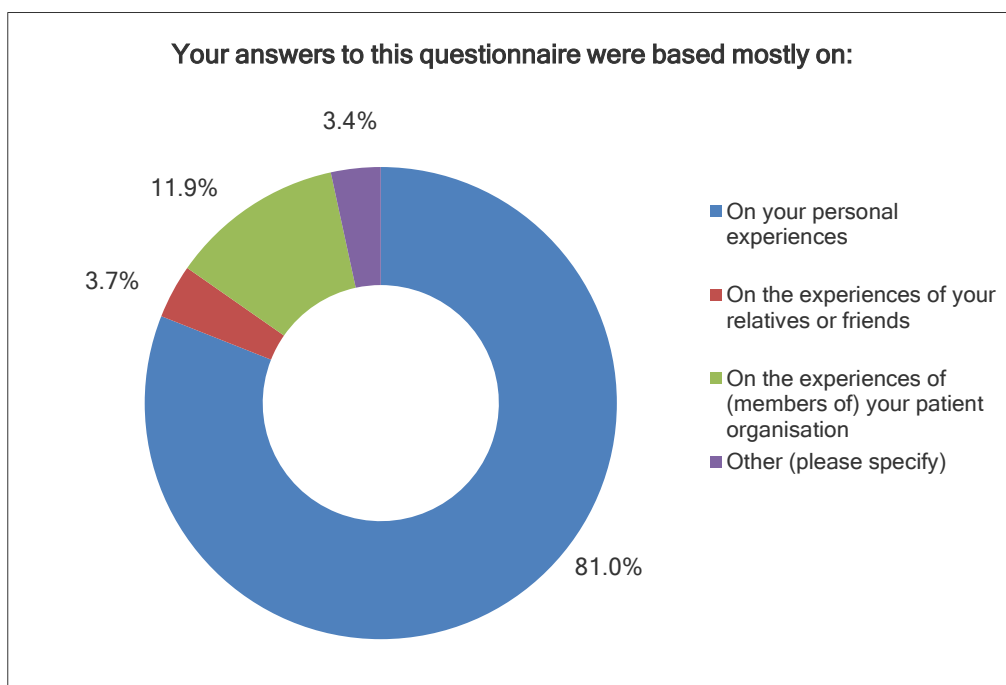
As we can see, most respondents referred to hospital care (119 respondents or 73%) and primary care (173 respondents or 64%), and the national healthcare system (202 or 75%). Surprisingly many respondents referred to healthcare provided in other long-term care organisations, such as care homes (110 or 41%).

In the free comment section, respondents gave more information on the kind of healthcare and environments they were thinking about. Different professions such as physiotherapists and dentists were mentioned by several respondents, as *chronic disease management* often involves multiple chronic conditions and different aspects of healthcare provision need to work in tandem: “other healthcare professionals that look after 'bits' of me or who are able to offer advice, support, medications if necessary and care when needed.” One commentator explained that hospital care also means outpatient/ambulatory care; and caring given by family or other loved ones was mentioned by more than one respondent. Diagnostics were considered a part of healthcare. One respondent explained that “public healthcare [means] planning how to look after a whole country” and community care, “knowing there is someone out there who can come and care for me if I need it, but in my own home.” Assistive devices, such as wheelchairs and mobility support were considered as part

of healthcare provision. Private healthcare was mentioned.¹¹ *Preventive care*, including actions taken by patients themselves to keep well and fit and self-care for the chronic condition itself, was mentioned as well as the workplace environment. *Mental health* was mentioned by more than one respondent, and one felt it ought to be included as a specific category in itself. Finally, *the wider community* including academic institutions, NGOs and community organisations, such as patient groups, were mentioned by some.

We also asked respondents to tell us whose experience they were thinking of when answering the questionnaire. A clear majority of 217 answered based on their personal experiences (81%), whereas 32 (12%) referred to the experiences of members of the patient organisation they represent, and 10 respondents (just under 4%) referred to the experiences of relatives or friends.

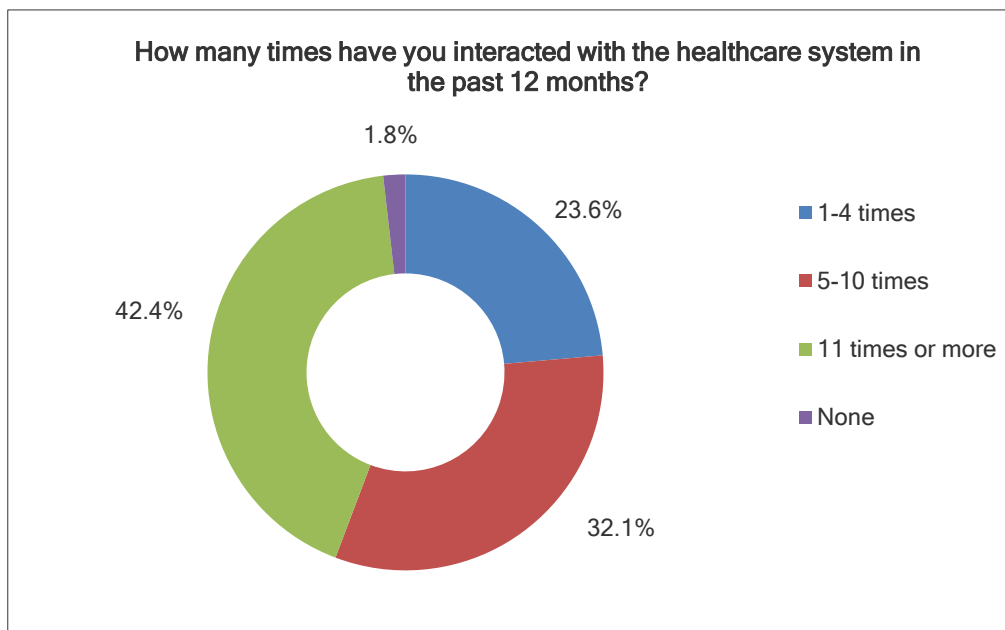
Chart 8: Whose experience (n= 268)



We also wanted to know how much interaction with the healthcare system the respondents had had in the past year. The majority of the respondents, 115 (42%) had had 11 or more interactions with the healthcare system in the past 12 months, whilst 87 respondents (32%) had interacted with the system between 5 and 10 times, and 64 (24%) between one and 4 times. Only five respondents, less than 2%, said they had no interactions with the healthcare system in the last year. This well reflects the target group of the survey, which was patients living with chronic conditions and shows that patients are by necessity forced to seek healthcare much more frequently than people without chronic disease.

¹¹ in the survey, we did not make any distinction between the provider of the care, whether it is private or public

Chart 9: Interactions with healthcare in the past year (n= 271)



3.3 PATIENTS’ DESCRIPTIONS OF “HIGH-QUALITY HEALTHCARE”

We asked the respondents to describe “high-quality healthcare” in their own words. There were 271 answers to this question. Despite some linguistic challenges in the analysis, we found these descriptions interesting and informative. It should be borne in mind that most respondents were not native speakers of English, and comments had to be provided in English. Therefore, it is possible that they might use the same word, but understand it differently; or conversely, they might use several different words for roughly the same concept. Most respondents were, however, quite articulate in their answers. We have tried to cluster similar words together. The table below shows the most frequently used words:

Table 1: Most commonly used words:

Care/caring	114	Safe	16
Patient/patients/patient’s	136	Effective	15
Best	45	Help/help/helping	15
Access/accessible/available	44	Competent/qualified/trained	13
Need/needs/needed	42	Information/informed	13
doctor/doctors	33	Diagnosis/diagnosed	12
Me/my	25	Individual/personal/tailored	11
Timely/fast/quick	25	Communication/communicate/talk/	
Listen/listening	18	explain	11
Professional/ professionals	18	Respect	10
Service/services	18		

Aspects that were often mentioned included:

- Being cared for as a person, not only a diagnosis or number; being treated with empathy and respect, in a holistic way, i.e., with consideration to psycho-social, mental and family aspects of illness together with the physical aspects.
- Achieving good quality of life; including better health outcomes but also enabling a patient to keep as active in society as possible when living with a chronic condition.
- Collaboration between professional and patient, the patient being listened to, and being an equal partner (and including family members/carers where applicable).
- Getting the best possible interventions, “best” being understood mainly as being accordance with the latest clinical guidelines and scientific knowledge.
- Timeliness of access to accurate diagnosis and follow-up treatment.
- Access for everyone who needs it according to needs, not means.
- Having time to talk with health professionals and enough information to support self-care.

Many respondents’ answers were aspirational towards universal access: affordability or low/no-cost, and accessibility mentioned many times. “offering the best possible service to all”, “offering the best treatment possible regardless of price”, “to have easy, free and fast access to relevant investigation and treatment”.

Most respondents addressed this question from an individual perspective, but some also said that quality of care is a system level issue and includes things such as well-trained staff and cost-effectiveness. A selection of comments is given below, clustered under different aspects that were frequently mentioned. The answers have been edited for clarification where needed.

Good quality of care is....

“Care that all persons can access and afford when they need, including the effective right of patient to be communicated all the content of [their] medical file and, on the other hand care involving a prompt and correct prevention, diagnosis, treatment and follow-up.”

Being listened to and taken seriously, partnership, support

“care that is adapted to individual needs of the patient and respects the patient’s choices and preferences. “

“Effective outcomes and a care system that is personal and coaches you through the disease without bureaucratic hassle.”

“When doctors and other staff actually listen to what I am saying.”

“When the patient is at the centre and the experts’ first question is to ask what matters to you.”

“Considering and listening to the needs of the patient to develop and direct care according to these needs.”

“Cooperation [between me and my health care professionals] means that I consult them on concerns and we find a solution to the problems together.”

“... Listening to me, believing in my observations, giving me choices, helping me decide, taking care of other aspects of my life than the illness itself.”

“to take the patient seriously... Professionals who can communicate with patients.”

“being treated by specialists who have time to listen and reflect in collaboration with the patient.”

“When the patient is heard and when the patient and doctor can work together.”

“To be heard. The feeling of ‘my opinion matters’ or is taken into consideration.”

“Listening to the patient.”

“listening – taking time to understand what the problem is.”

“Being listened to by one’s doctor. Being helped with illnesses in a way where you yourself are actively involved. Having the same doctor and nurses who know your history. Not having to wait too long for diagnosis or medication.”

“Making sure the patient is feeling part of the process.”

“placing the patient first in all areas.”

Good quality of care is....

“To be able to visit the doctors when you meet without long waiting or paying. In addition, quality of care is to have access to the right form of medication. But above all, quality of care for me is to fully communicate with the doctors and the medical team for the greatest results.”

Quality of life

“Life without pain.”

“Able to live a normal life within the possible.”

“Care that is effective in resolving the medical issue or supporting a patient as high quality of life as possible while still having a (long-term)” condition. It looks forward to prevent illness and distress, works with the patient and family/carers to keep the patient in as good a quality of life state as possible (QoL must be defined by the patient, not a ‘scorecard’) and looks to the past to see if anything could be done better for other patients/prevent the medical issue arising etc.”

“listening to the patient, using the very best medicine, so that the patient can leave as normally as possible.”

“That you receive proper care or treatment that makes it possible for you to live with the disease.”

“When you are well treated medically in your life quality is high, despite your disease.

“When you don’t have to worry about your disease.”

“Giving advice on all aspects of my illness in a holistic, integrative approach”

“understand my situation (disease impact and social circumstances)

“to care and try to improve patients’ life!”

Good standard of treatment, that is up-to-date, given by professionals that are well-trained

“Being treated in secure healthcare environment, with latest available interventions and medicines, respecting human and patient rights and in an empathetic atmosphere.”

“When a patient has access to the best possible therapy, expertise and treatment whilst being an equal partner in care.”

“Care based on best practices, supported by scientific evidence.”

“when a patient has access to the best possible therapy, expertise and treatment whilst being an equal partner in their care.”

“... the degree to which [the healthcare system] treats medical problems according to up-to-date professional guidelines.”

“done by experience and professional people, in time.”

“Attention from relevant experts and qualified people.”

“provision of standardised treatment according to European recommendations.”

“when patients have the right to have the best healthcare that his or her disease requires from all angles, doctor, medicine, physiotherapist, psychology, nurses, state support, etc.”

“effective, safe and respecting the quality standards in place.”

Good quality of care is....

“Timely diagnosis with good accident and emergency services, quality skilled medical professionals in easily accessed centres of excellence in good geographical locations from birth to death. With excellent research and [clinical] trial opportunities. Hospice care and palliative care. Treatment and counselling with holistic attitudes to patients and families”.

Information and communication

“When the doctor has time to listen to you and the time to pick out the best course of treatment. With that said they should not be pushovers and should stand their ground based on experience in the field. They should also be able to communicate their reasoning and make the patients understand why the choices are made.”

“When shared decision-making is common practice and include patient friendly and relevant information.”

“Professional people who are willing to communicate with the patient in such a way that the correct care will be given.”

“making sure that patients understand what they are being informed.”

“Timely, evidence-based, effective and safe healthcare service offered to the person in response to his/her needs and delivered after the patient’s informed decision.”

“Possibility to choose from a wide range of alternatives for which informed consent is needed.”

The human face of healthcare

“When you are taken care of as a whole, as a patient and as a person with a context.”

“Being listened to by one’s doctor. Being helped with illnesses in a way where you yourself are actively involved. Having the same doctor and nurses will know your history. Not having to wait too long for a diagnosis or medication.”

“Pay attention to patient, not just the diagnosis.”

“Knowing that the patient has a name and is not a number. And knowing who is your personal doctor.”

“Personnel listening and caring about you and your wishes.”

“Being cared for.”

“The doctors to be able to put themselves in the patient’s shoes.”

“With the head [and] with the heart.”

“With the head [and] with the heart.”

“To be treated as a human being.”

Good quality of care is....

“when you are provided with the best known care at the right time and the right place from the right persons, no more no less, and that the care and treatment is evidence based. It is also important that the different [parts of the healthcare system] work well together.”

Financial issues and easy, quick access

“Getting treated fast and accurate.”

“To be taken care of when ill or injured, without having any concerns regarding economy and if the treatment is good enough.”

“To not have to wait for 6+ months to see a doctor. To not go broke because you have to meet with your doctor or are on meds to keep you alive. That when you get really sick there is room for you at the hospital and you don’t have to worry about being forgotten.”

“Access to an effective health care for everybody.”

“You get the best care you need and not the cheapest.”

“provisions and facilities that guarantee all citizens adequate and unrestricted access to health and medical care and treatments.”

“[the treatment] you need, when you need it.”

“Offering the best treatment possible regardless of price!”

“Free health care with fast access to it.”

“Not having to worry about costs”

“Care should be equal for all, regardless of where they live, what religious and ethnic background they have, what gender and what social class they belong to.”

Trust

“When I trust my doctor.”

“Always walking home from the hospital with fewer questions/worries than before.”

“The feeling that you are in competent hands.”

“Being able to trust that you get the best medical and psychosocial care available at an affordable price.”

“To be able to trust that your doctor, nurse, hospital provides professional healthcare and know what they are doing.”

“Making patients feel safe and confident.”

3.4 WHAT IS MOST IMPORTANT TO PATIENTS?

Arguably, all aspects of quality are important. We asked several questions with a similar aim: to get some differentiation between various aspects of quality in healthcare to see if patients would prioritise some aspects over others.. As we will see in the discussion, below, the responses here should be treated with some caution: many respondents felt it was very difficult or impossible to choose priorities between different aspects.

3.4.1 Rating of Different Aspects of Quality

We first asked patients to rate aspects of quality that matter most to them, by arranging the 13 given options from most to least important.¹² (Please note in the table below we give actual respondent members rather than percentages.) in the table below, we have highlighted the three most scored ratings for each aspect of quality, to give an indication of where they are positioned on the scale of most-least important. As we can see, however, there is substantial variation in the spread for most aspects.

Table 1: Patients’ prioritisation of aspects of quality (n= 271)

	Most important Least important												
	1	2	3	4	5	6	7	8	9	10	11	12	13
Positive attitude of healthcare workers towards patients	31	18	23	22	21	24	24	28	21	20	23	11	5
Staff have good communication skills	12	21	14	21	19	20	25	34	23	27	27	20	8
Healthcare system is inclusive towards vulnerable groups	10	13	23	13	14	18	19	13	29	29	25	30	35
Accurate diagnostic procedures	57	45	29	36	14	21	16	17	10	11	8	3	4
Timely diagnosis, treatment and follow-up	36	38	32	25	35	32	17	17	13	11	9	3	3
Treatment that is clinically effective	26	27	40	23	35	31	21	17	9	19	12	9	2
Latest treatments are available	16	22	24	29	20	25	26	15	20	25	21	19	9
Healthcare environment is aesthetic	10	4	1	4	4	1	5	12	13	14	23	47	133
Public investment of resources in healthcare	12	9	10	11	15	14	24	21	37	31	26	41	20
Treatment and care is safe	24	23	28	23	24	25	18	31	20	24	12	15	4
Services are affordable for patients	9	15	13	14	23	20	24	18	30	28	32	27	18
Consideration of individual needs and preferences	8	21	16	21	28	21	23	24	22	19	31	25	12
Patient participates in shared decision-making	20	15	18	29	19	19	29	24	24	13	22	21	18

We can see that accurate diagnostics are consistently rated towards the high end of the spectrum. This is quite consistent with the feedback given to EPF in the past by many patients that they found it difficult to obtain an accurate diagnosis of their condition, which could sometimes take many years.

¹² based on WHO and the feedback from EPF PAG.

As we can see, the one aspect which consistently comes bottom is the aesthetics of the healthcare environment. We can also see that access-related factors – inclusivity of the system towards vulnerable groups, Public investment of resources, and affordability also skewed towards the less important end of the spectrum.

The spread and patient safety is very wide, where based on previous feedback we would have expected it to be consistently ranked high. Similarly, the ratings of healthcare professionals’ attitudes, consideration of individual patients’ preferences and shared decision-making are ranked somewhat lower than we would have expected.

We then asked patients to describe other factors of good quality healthcare that were not mentioned in the previous question, if any.

Several respondents said the ranking was not useful because they felt all aspects were important.

“All the options for me are almost equal, it was hard to make an order of preference.”

“The above are nearly impossible to put in order as mostly equally important. 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.”

“All these factors are important so making on rank them is almost impossible and it changes with each bout of experience - diagnostics, accuracy, empathy, are all pointless if patients can't afford them - patients having a voice and empowerment is key in all of these”

Nevertheless, some interesting opinions emerged, with the following being recurrent: mental health and a “holistic approach;” training of healthcare professionals; involvement of the family, especially when patients are vulnerable; partnership with patients; patients’ health literacy and support to manage illness; reference to human and patients’ rights; access or coverage issues, such as the right to a second opinion, complementary therapies, and choice between public or private provider (with same cost); and the role of prevention, rehabilitation at other services.

Below are selected comments illustrating the above (edited for clarification/English):

“Human and patient rights (no discrimination, informed consent, confidentiality).“

“Kindness and compassion is important and high ethical standards.”

“That healthcare is non-discriminatory – equally available at high level of quality to everyone, regardless of cost.”

“Patients are involved and represented at each table where decisions regarding healthcare are made.”

“Equal and universal access/”

“Personalised medicine: what is effective in a large group of patients may not be effective for you and vice versa.”

“Adequate time when consulting a doctor or specialist; is now mostly too short especially when you prepare your questions before the session.”

“Psychological and social support for the people caring for the patient.”

“Preventive health care is of the utmost importance, campaigns and screenings targeting socio-economically vulnerable segments of the population in order to provide equal health and life expectancy for all.”

“What is available through the healthcare system is not necessarily what is needed by the individual ... A long-term and holistic approach is needed. Drugs are not the only remedy; we need to apply psychological and behavioural measures as well. And recognizing the values of interventions of this character as well. Channelling of funds accordingly.”

“Possibility to choose from wide range of alternatives - specially in mental health field. Over-medicalisation is problem in mental health care that destroys physical health ... Psychotherapy is underfunded and thus is out of choice usually.”

“No bureaucratic hassle - making appointments, invoices, getting prescriptions, etc. ... is all made very easy and seamless”

“Being given *all* information.”

“Integrated healthcare!! Communication between professionals is a crucial factor for the diagnosis and care of long term, complex conditions.”

“Having a standard of care in Europe/the world.”

3.4.2 Top six dimensions of quality

We asked patients to select six “top” areas of quality from amongst 11 options. Some of these dimensions were similar to the priorities in a previous question. The categories were explained as follows:

Timeliness: Healthcare services that are provided promptly at the right time.

Cost-effectiveness: Treatments and services that provide value for money.

Evidence-base: Treatments that are evidence-based.

Efficiency: maximising use of resources and avoiding waste.

Up to date: Use of modern and appropriate technology.

Safety: maximisation of safety and minimisation of harms.

Workforce skills: appropriate skills and knowledge of healthcare workers.

Equity: fair access, non-discrimination.

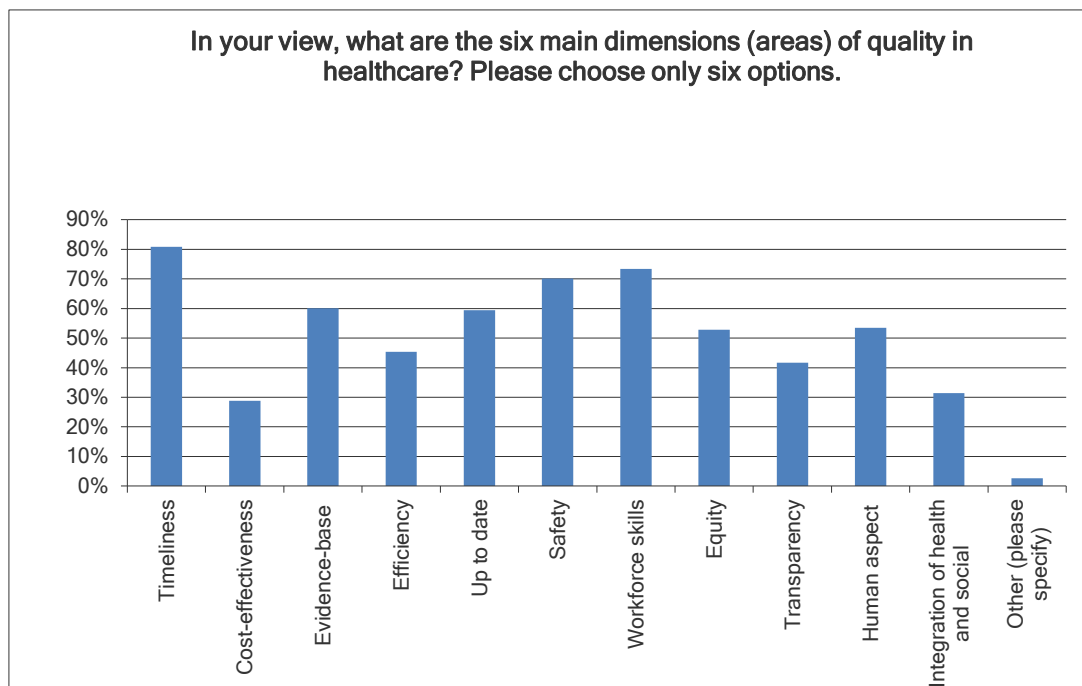
Transparency: transparency of the healthcare system towards patients and citizens.

“Human face”: humane response towards patients.

Integration: joined-up health and social care services.

The six most frequently selected aspects were timeliness, selected by 219 respondents (81%). This was followed by workforce skills (199/73%), safety (190/70%), evidence base (163/60%) treatment that is up-to-date (161/59%), and the human face of healthcare (145/54%). Equity was fairly close behind, however, with 143 ticks. The two aspects that clearly received fewest votes were cost-effectiveness with 78 ticks (29%) and integration of health and social care with 85 ticks (31%).

Chart 10: patients’ prioritisation of aspects of quality (n= 271)



In comments, respondents mentioned the importance of community involvement and different areas of the healthcare system working in tandem, as well as the importance of outcomes (“a health care system that does not deliver meaningful outcomes is a waste of resources”). Patient-centeredness was mentioned, as was quality of life, specifically as an indicator of effective treatment in mental health. It should be noted that in this question, patient-centredness was not one of the options in itself.

3.4.3 Perceptions of the 6 dimensions of quality in the WHO definition

Quality of care has been defined by the World Health Organization (WHO) as follows: Care that is effective, efficient, accessible, acceptable/patient-centred, equitable and safe.¹³ We asked whether respondents agreed with these six dimensions of quality.

The six dimensions were described as follows:

¹³ Quality of care: a process for making strategic choices in health systems. WHO, 2006. pp. 9-10. www.who.int/management/quality/assurance/QualityCare_B.Def.pdf

Effective: Delivering health care that is adherent to an evidence base and results in improved health outcomes for individuals and communities, based on need.

Efficient: Delivering health care in a manner which maximizes resource use and avoids waste.

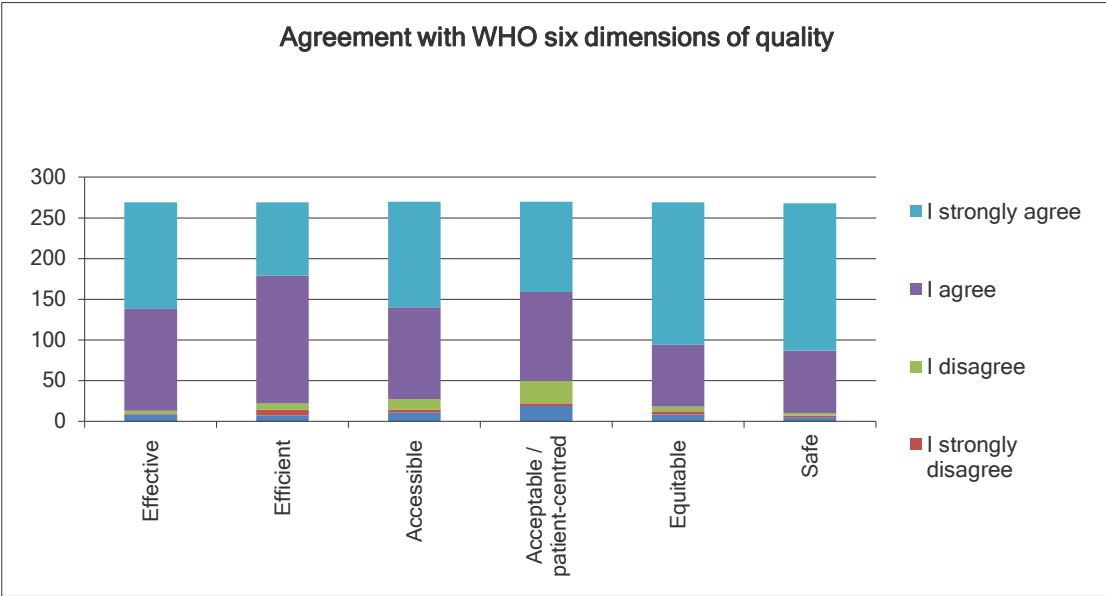
Accessible: Delivering health care that is timely, geographically reasonable, and provided in a setting where skills and resources are appropriate to medical need.

Acceptable/patient-centred: Delivering health care which takes into account the preferences and aspirations of individual service users and the cultures of their communities.

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.

Safe: Delivering health care which minimizes risks and harm to service users

Chart 11: Agreement with WHO six dimensions of quality (n= 271)



A majority of respondents agreed or strongly agreed with all six dimensions. Interestingly, the dimension where there was most disagreement was acceptability/patient-centredness, with which 31 respondents (11%) disagreed (although only 3 disagreed strongly), and 19 (7%) chose “don’t know/no opinion”. Despite the broad agreement, some interesting comments were received and these dimensions:

“Under 'equitable' one of the personal characteristics [on non-discrimination] should be mental capacity.”

“[often patients are left on] waiting lists. Help may come too late”

“Equitable access is a broader concept than variation in quality based on personal characteristics. Variations within and between EU Member States exist (we simply don't measure them). I am fortunate to have access to a number of GP in my local municipality. I do not know which of them is better at treating my chronic diseases.”

“I believe patient-centredness should be transversal to all other dimensions.”

“I agree with "Efficient "Delivering health care in a manner which maximizes resource use and avoids waste.” but sometimes I have the feeling that this dimension is too much privileged by hospitals and doctors, regarding the cost of treatment.”

“I disagree with the area "Efficient", because this is not for the benefit of the patients but rather for the benefit of governments and businesses. What may be the effect of such promotion of efficiency, is that in order to avoid "waste" of resources, not enough resources will be allocated and specialists will be asked to work on the limit of their abilities which will result in burn-out and lack of attention (this is very often the case in psychiatry). Besides, self-help groups and other good practices may be easily considered like a "waste" of resources (which again is the case in Europe), and healthcare will be limited only by pharmacological treatment. So, it is safer to allow for some waste of resources to ensure quality care in result.”

“In general I think there are no "unimportant" aspects. My answers might be inconsistent therefore.”

“In psychiatry complaints of patients are often dismissed as the symptom of illness. Safety in psychiatry is very important as long-term usage of medication does "more harm than good" and is linked with increased chronicity.”

“I would add "disability" to the list of characteristics in the penultimate statement.”

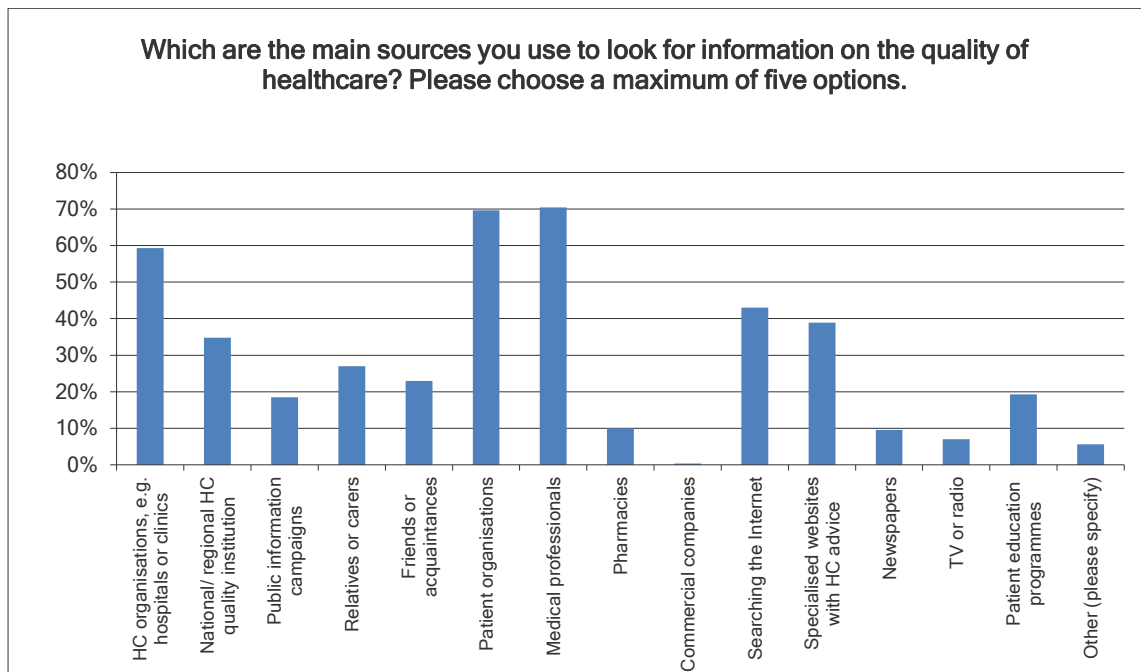
“Sometimes risky treatments are necessary.”

“I think "safe" should be defined in the perspective of the actual outcomes. I don't mind my chemotherapy being aggressive, as long as it kills the cancer cells.”

3.5 WHERE DO PATIENTS GET INFORMATION ON QUALITY OF HEALTHCARE?

We asked about the main sources respondents use to look for information on the quality of healthcare. They were able to select a maximum of five options from the list and also provide comments.

Chart 12: Sources of healthcare quality information (n=271)



The most often mentioned sources were medical professionals (for example doctors and nurses) with 190 mentions (70%) and patient organisations with 188 (69%). Healthcare organisations came third, with 160 mentions (59%), and “Dr Google” was mentioned by 117 respondents (43%). Also frequently mentioned were specialised websites (105/39%). Interestingly, over a third had looked for information from national or regional healthcare quality institutes.

The least mentioned were commercial companies with only one single mention, TV or radio with 19 (7%) and newspapers with 26 (9%). Interestingly, pharmacies were mentioned only by 27 respondents. Seventy-three patients would ask relatives or carers (27%), and 62 would ask friends or acquaintances (23%).

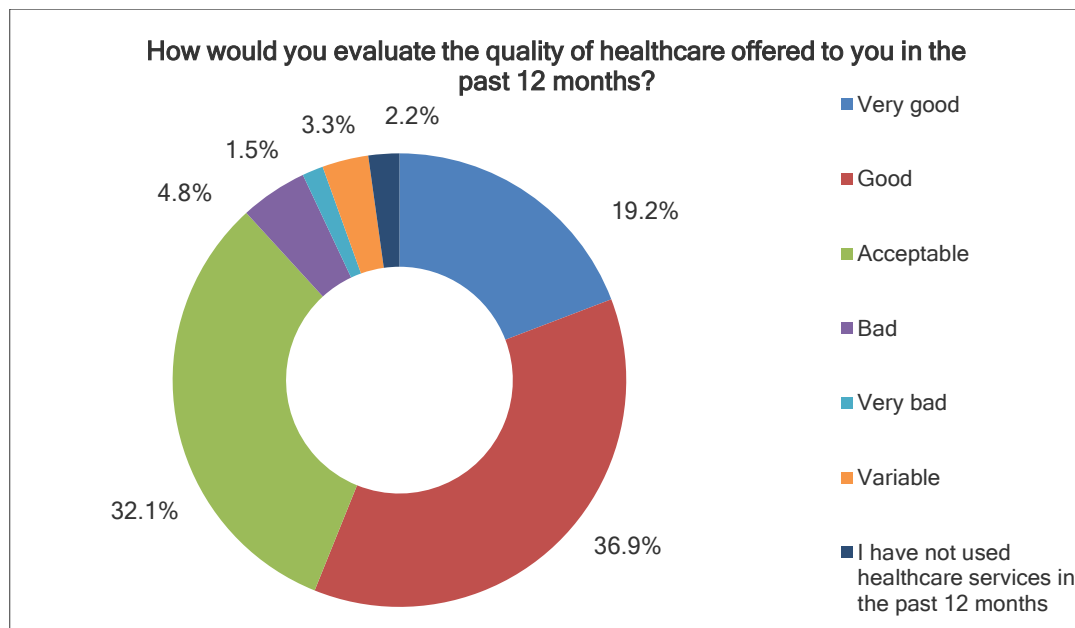
“Specialised websites but I personally only use hospital or medical journal websites, never blogs or self-declared health experts, or ‘doctors’ who are selling something. There are a worrying number of these ... and people who believe in them because the person is Dr somebody.”

In the comments, some respondents mentioned academic books or publications and sites such as PubMed. There were also a couple of mentions of social media (Facebook). One respondent said s/he did not look for information as “I expect to be getting the best healthcare I can be provided”.

3.6 VIEWS ON HEALTHCARE QUALITY OFFERED

At the end of the survey, we asked what the respondents thought about the quality of healthcare offered to *them* during the past 12 months.

Chart 13: Respondents’ evaluation of the quality of healthcare (n=271)



Overall, respondents perceived the quality of care as good or very good, with 100 respondents rating it is good and 52 is very good (37% and 19%, respectively) whilst 87 respondents (32%) said it was acceptable. A minority of 6% (17 respondents) the care had been bad or very bad, whilst 9 (3%) said it was variable.

3.7 WHAT NEEDS TO CHANGE

We asked respondents to describe in their own words the main change they would like to see happening in order to improve the quality of healthcare. Below is a summary of the most commonly featured aspects, and a selection of answers (edited only for clarity/English).

Access is mentioned 22 times (and **affordability** four times).

“Shorter waiting times in hospitals.”

“Better access to a doctor and modern drugs and the elimination of bureaucracy.”

“Fairer system and reduced costs to increase access to medicines.”

“Easier access to public healthcare because there are many patients who cannot afford to pay for private healthcare in Portugal.”

“The waiting time for the services is nowadays often too long.”

“Faster access to specialized medical expertise and (diagnostic) treatment.”

“More treatment and I should spend less time demanding that I get the treatment that they should have given me in the first place.”

“People with the same diagnosis have different access levels depending on in which region they live.”

“Faster access to consultants.”

“That the care becomes more important than the cost of money.”

Better communication was mentioned 11 times.

“Improve the social skills of the staff.”

“Better communication between healthcare providers and patients.”

“More credit given to the art of conversations as the individual patient has lived experience of what it is like to live with their condition and they need to be listened to more often.”

“Many terms used by medical professionals, are not easy to understand for the common man. It should not be necessary to learn Latin to understand your diagnosis.”

More time was mentioned 10 times.

“More time for physician-patient communication.”

“More time to listen to the patient.”

“TIME! Remember that patients are more than just a diagnosis. I have suffered from a chronic disease the last 40 years, and within this period much has changed in the healthcare system. Because of lack of time and too many different people being involved in your treatment, too many mistakes happen, e.g. mistakes in medication.”

“My consultation with the doctor is set for about 4 minutes. I'm chronically ill, I have A lot of questions. I'm unsure. Feels unsafe. And there is no time for that.”

Strengthening the **role of patients, including patient organisations' role** in civil society was also frequently mentioned.

“The improvement of patient literacy and participation on healthcare delivery.”

“Well informed patients that are able to ensure they are getting the best healthcare available – if the consumers are effective advocates for themselves and their peers changes for the better happen.”

“The patients to have full access to their medical record and results and those being explained rather than kept away from patients.”

“I would like to be given far more information about my condition, ie given copies of reports of scans and pathology reports and blood results in full. I always feel that things are being kept from me and I feel that it's my body, my health, and therefore I should not be kept in the dark.”

“I want to be a part of my Own treatment. I'm a person, not a number. I want my doctors to see me like that. And to LISTEN. Even when the data says something else.”

“Some more follow up on patients. You feel very much alone when you are diagnosed with a chronicle disease.”

“Treating the patient as a partner, not as a sick, voiceless thing.”

“I am extremely satisfied (and alive). My wife sometimes complains that she was left with her fears, so I guess better integration of the family in the process might help too.”

“Integrate patient and civil organizations in the health system.”

“Healthcare professionals should automatically refer to patient organisation to help the patient to better understand their own disease (professionals often don't have enough time to make sure that the patient understands everything).”

Skills and attitudes of healthcare professionals, but also an acknowledgement of the **stress** they are under (professionals' stress as a safety and quality issue was mentioned four times).

“I believe in the skills and knowledge of health professionals, but I think that still exists in the health service a lack of humanity both in administrative personnel, as in healthcare professionals.”

“The relationship between patient and healthcare professionals.”

“More understanding from hospital employees and more employees in the hospitals period. They are way too stressed out, and stress leads to errors and neglect.”

“That the personnel was more active with the patient and made them feel welcome and not like a burden.”

“Take patients seriously. When things like lupus remain undiagnosed, some doctors treat patients as though they were mentally perturbed when they tell their symptoms. That makes it even worse for someone suffering such illness, looking for a diagnose and a treatment to feel better and getting stared at or talked to as a weirdo.”

“That doctors realize that the patient might have own ideas about the treatment and become better to listen.”

“A friendly and empathetic face is also nice to have, but should not be valued higher than skills of the healthcare professional.”

Integration of care

“In my country, healthcare needs to be more “joined up”. I have several conditions and so see several different consultants in acute/secondary care. I also have a GP. The only link between all of these people is me – I end up having to write letters to all of them each time I see one of them to let them know what the test result set, or that I'm taking a new medication – I am my own “care coordinator”. As a result of this, my care is okay as each of them knows what the other knows – but I never know what I might be missing out on because I don't know what else is available.”

“More personalized, meaning having the same healthcare persons all the way though the treatment/stay in a hospital.”

“Less change of healthcare personnel. More continuity in doctor conversation.”

“Improve coordination between the various specialities ... in dealing with diseases such as lupus that require assistance from all of them.”

“From a purely personal point of view, as a person suffering from several chronic (but distinct) conditions, integrated care, with doctors talking to each other, would make life a lot easier. Although specialisation is good and necessary, it does also lead to “boxes” of knowledge and things being missed because they are outside the speciality of the person you are seeing. In this way I have missed several years of quality of life and work life, something that could have been avoided by, quite literally, thinking outside the box.”

Specific concerns in mental health:

"Healthcare must respect human rights standards and must build its systems around these core standards rather than thinking about them as something extra, and quite distant. This involves informed decision-making, prohibition of discrimination, equity, cross healthcare cooperation (connections between somatic and mental health services, reproductive health for every group of patients), cooperation with social services and patient-centeredness. More specifically, for mental health, we would like to see deinstitutionalization and quick development of community services, with complete prohibition of forced treatment."

"Awareness that mental health patients need not only medications, but also effective psychotherapy, [religious] care, social care and removal of stigma."

"Informed consent and possibility to choose from wide range of alternatives specially in mental health."

More transparency, both in the patient-professional relationship and at societal level in how healthcare funding is spent.

"Safe hospitals, well prepared doctors, better and in time diagnosis, better transparency in the spending of our money."

"The healthcare system must be more organized and with more transparency mainly in the relation patient / professionals."

"Enforcement and regular assessment of evidence-based procedures on patient safety and health interventions."

"politicians educating the public that cost-effectiveness must be an important element in deciding what will be reimbursed and what not."

Organisation of healthcare

"Improved communication between different specialties and between primary and secondary care. Move from paper based to entirely electronic care records that can be seen by all practitioners. More financial resources."

"In Scotland, health and social integration has begun, but needs to progress faster and be accurately measured. Too much confusion and 'pass the buck' mentality."

"Better procedures, less time spent in the waiting rooms ... and cleaner hospitals."

"Less waste, better time management, better communication. Less double testing because off egos."

"Better organisation of hospitals. Meaning that professionals have more time to each patient."

"More healthcare in my home (through technology)."

"I would like healthcare systems to focus on measuring outcomes and less on measuring inputs. With an ageing society and chronic diseases we will need to allocate additional funding to healthcare. If we measure only inputs then we may develop cost-efficient healthcare systems but we will have little or no idea as to whether the resources we spend deliver meaningful patient-centric, clinically relevant health outcomes."

"Patient outcome measurements, also other values than being effective, also the definition of being 'effective' should be enlarged."

"Stop the bureaucracy."

(Under)funding of healthcare systems is a concern.

“I would like to see the departments and hospitals get the funding they need to be able to provide a service level with which they are contented with themselves.”

“I wish more financial resources were devoted to healthcare.”

“It would be great if my countries healthcare authority start investing more in health and understands that such investment will be of long-term benefit.”

“Financing on real value of the healthcare services.”

“More nurses.”

“That the system could get more money so they don’t have to reduce all the time.”

“More public funding for research into new treatments.”

“To have a national health system in my country.”

4. Discussion

As we stated above, the survey is not intended to be scientific, as its purpose is to gather patients' perspective is to inform EPF's advocacy work. Nevertheless we wish to point out some limitations.

Demographics

There is a significant gender imbalance in the responses, as women made up 71% of the respondents. Also, in terms of age, the young patients' perspective is not really included, because only seven respondents were under the age of 21.

An anomalously large number of responses – over a third – were received from Denmark. The reason for this is not known. From several countries there were few responses, and only one each from Austria, Croatia, Estonia and Slovakia. No responses were received from the Czech Republic, Latvia and Luxembourg. Nevertheless, we can say that responses were received from the majority of EU Member States.

We did not ask about the respondents' condition or disease-area. Therefore, we do not know to what extent different disease-groups were represented.

The answers

The results on the ranking questions appear partly contradictory with each other and with the "in your own words" descriptions. For example, access emerges as a clear priority concern in the descriptive answers. However, access-related factors were ranked broadly as lower priority in question 9. Similarly, safety is usually rated as a high priority, and indeed question 11 confirms that this is so. Against that, the answer to question 9 appears odd. Healthcare staff attitudes are prioritised in question 9, but communication skills are not, even though communication emerges as another key priority in the descriptive answers.

This should in our view not be interpreted as indicating that these are not important for patients. We speculate that when having to put priorities in order of importance, whilst thinking about the *quality* of healthcare, respondents may have considered access as being a characteristic of an equitable system as a whole, rather than quality *in a strict sense*. It is also possible that when participants have to prioritise, more concrete and objective criteria such as effectiveness, accurate diagnostics and timeliness take priority over more personal ones. Communication skills may have been perceived as falling under another topic.

It should also be noted that several respondents said it was very difficult to assign priority as they felt all or most of the aspects were important. For example, it is not possible to rank safety and clinical effectiveness, one above the other. It was also pointed out that "what matters" may be highly context-specific, different with each individual experience or interaction with the health system. The prioritisation exercise was indeed somewhat artificial, and it would appear to confirm that patients perceive of "quality" as a very multi-faceted concept that comprises all aspects of healthcare.

“There is no point in having effective/latest treatment if no one can afford it but equally, without correct diagnosis, people die... Also without including the patient, i.e. listening to them, the treatment cannot be effective... And although low on my list (something has to be), if the communication skills are not there, the patient isn’t being listened to, things are being used, 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.”

5. Conclusions and recommendations

We already know that patients with chronic conditions by necessity need to seek healthcare (and social care) services more often than other people. They are thus dependent on accessible, effective and high-quality healthcare provision much more than the average citizen. This is borne out by the responses to our survey. Almost half of the respondents, 42%, had had 11 or more interactions with the healthcare system in the past 12 months, whilst a third had interacted with the system between 5 and 10 times. Overall, they rated the quality of the care they had been given as good, which is a positive finding as these are frequent users of healthcare services. (Nevertheless a minority of 6% who said that quality was bad or very bad is not negligible.)

Because patients with chronic conditions have such frequent and long-term experience of the healthcare system, their perception of healthcare, experience of the care process, and evaluation of various indicators may therefore be different from that of the general population.

We can see that accurate diagnostics are consistently rated towards the high end of the spectrum. This is quite consistent with the feedback given to EPF in the past by many patients that they found it difficult to obtain an accurate diagnosis of their condition, which could sometimes take many years. Possibly for this reason, timeliness of diagnosis and prompt treatment is also highly rated.

Patients also expressed strong wishes for better communication, more information, and a more genuine partnership with the healthcare professionals, willing to take on a more active role in their care – or a greater recognition of all that they already do.

The involvement of patients – individually and collectively – in evaluating and co-designing healthcare services is in our view vital to ensure that the latter work better for all users. This is even stated in the Regulation setting up the Third EU Health Programme: “Healthcare practices should be informed by feedback from, and communication with, patients.”¹⁴

¹⁴ Regulation (EU) No 282/2014, recital 12

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.

Good quality of care is....

“Care that fulfils the following aspects: respectful treatment and privacy, good information and communication, accessibility and affordability, user involvement, empowerment, (medical) expertise, patient rights, continuity of care, tailored care, patient safety, outcome monitoring.”

It is also crucial to empower patients in all aspects of health and care through high-quality information and by building *health literacy*.¹⁵ Health literacy is a key dimension of patient empowerment, and highly relevant to patient safety and quality.¹⁶ Low health literacy is associated with reduced use of preventive services and management of chronic conditions, and higher mortality.¹⁷ It can also lead to problems such as medication errors, misdiagnosis due to poor communication between providers and patients, low rates of treatment adherence, hospital readmissions, and other related complications or conditions.¹⁸

Health literacy also 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.¹⁹ 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 respondents wish for more information, full and clear explanations.

¹⁵ Health literacy entails 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. Sorensen K et al., Health literacy and public health: A systematic review and integration of definitions and models BMC Public Health. 2012

¹⁶ See EPF paper on patient empowerment (2014) available at www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/Background-papers/

¹⁷ Berkman ND et al., Literacy and Health Outcomes; AHRQ; Rockville, MD, 2004

¹⁸ 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

¹⁹ “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/>

Patient involvement in quality of care 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” for improving the quality and efficiency of healthcare. They can play an active role in care, becoming partners or “co-producers” of well-being, if given the opportunity and support to do so. Patients, families and carers to their representative organisations also play an important role in awareness raising and capacity building around safety and quality of care.

EPF believes that the patient experience should be adopted as a key evaluation tool in assessing the quality of healthcare and health systems’ performance. 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.

Meaningful patient involvement as defined by EPF is based on the premise that patients have a specific expertise and knowledge derived from lived experience. Only the patient sees the “whole journey.” We can identify gaps in services, but also superfluous or unsolicited services, helping make healthcare both more effective and more efficient.

EPF believes that the patient-prioritised outcomes as well as the patient experience of care should be included as indicators for assessing the quality of healthcare and health systems’ performance. This does not mean using “patient satisfaction surveys” as a tick-box exercises, the incorporation of meaningful measures – including, where necessary, qualitative – for outcomes and care processes.

Next steps

In 2017 EPF will develop a position paper on quality of care, in consultation with our members, and taking into account the results of this survey. We may decide to explore some of the aspects of the responses further with individual patient representatives who agreed to be contacted.

6. Annex: Survey questionnaire

I. General information about you

1. * Are you... ?

- A patient
- A family member or informal carer
- A representative of a patient organisation
- Other (please specify)

2. *What is your age?

- 17 or younger
- 18-20
- 21-29
- 30-39
- 40-49
- 50-59
- 60 or older

3. * Are you... ?

- A man
- A woman
- Prefer not to say

4. * Please select the country where you live:

[country drop-down list]

5. *Are you active in a patient organisation?

- Yes, in a patient organisation functioning at national/regional/local level
- Yes, in a patient organisation functioning at European or international level
- No.

6. *How familiar are you with the concept of “quality of healthcare”?

Please select only one answer.

- Very familiar
- Quite familiar
- Somewhat familiar
- Not much
- Not at all.

II. General questions about quality of care

7. *In your own words, how would you define “high-quality healthcare”?

Please complete the following text in the box below:

"Quality of care is"(please complete the phrase)

8. *When you think about “healthcare”, which healthcare environment do you have in mind:
(tick all that apply)

- Primary care (e.g. care provided by family doctor)
- Healthcare provided in a long-term care organisation (e.g., old people’s care home)
- Healthcare provided at home by healthcare professionals (home visits)
- Hospital care
- The national healthcare system
- Other (please specify)

9. *When you think of good quality of healthcare, what is most important to you?

Please number these options from 1 to 12, where 1 is “most important” and 12 is “least important”.

- Attitudes of healthcare workers towards patients are positive (e.g., respect, empathy)
- Communication skills of healthcare workers are good
- The healthcare system is inclusive towards vulnerable or discriminated-against groups
- Diagnostic procedures are accurate-
- Diagnosis, treatment and follow-up is timely (quick)
- Treatment is clinically effective
- All the latest treatments are available to patients
- Healthcare environment is aesthetically nice
- There is public investment of resources and funds in healthcare
- Care/treatment is safe
- Cost of the services for patients is affordable
- Consideration of patients’ individual needs and preferences
- Patient participates in shared decision-making

I wish to add another important factor (please describe):

10. *In your view, what are the six main dimensions (areas) of quality in healthcare?

Please tick only six options. (Note: some of these “dimensions” may be similar to the priorities you chose in the previous question.)

- Timeliness: Healthcare services that are provided promptly at the right time
- Cost-effectiveness: Treatments and services that provide value for money
- Evidence-base: Treatments that are evidence-based
- Efficiency: maximising use of resources and avoiding waste
- Up to date: Use of modern and appropriate technology
- Safety: maximisation of safety and minimisation of harms

- Workforce skills: appropriate skills and knowledge of healthcare workers
- Equity: fair access, non-discrimination
- Transparency: transparency of the healthcare system towards patients and citizens
- “Human face”: humane response towards patients
- Integration: joined-up health and social care services

Other (please describe):

The World Health Organisation (WHO) considers that health systems should seek to make improvements in six areas or dimensions of quality: (1) effectiveness, (2) efficiency, (3) accessibility, (4) acceptability/patient-centredness, (5) equity, and (6) safety.”

11. *How does this definition compare with your perception of quality? The meaning of each of the WHO dimensions is explained below. You can provide a brief explanation for your selection if you wish, using the free text box.

	I strongly agree	I agree	I disagree	I strongly disagree	I don't know / don't have an opinion
Effective “Delivering health care that is adherent to an evidence base and results in improved health outcomes for individuals and communities, based on need.”	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Efficient “Delivering health care in a manner which maximizes resource use and avoids waste.”	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accessible “Delivering health care that is timely, geographically reasonable, and provided in a setting where skills and resources are appropriate to medical need.”	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Acceptable / patient-centred “Delivering health care which takes into account the preferences and aspirations of individual service users and the cultures of their communities.”	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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.”	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Safe

“Delivering health care which minimizes risks and harm to service users.”

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Do you wish to comment on your answer?

12. * Which are the main sources you use to look for information on the quality of healthcare?

Please tick maximum five options.

- Healthcare organisations (e.g. hospitals or clinics)
- National or regional healthcare quality institution
- Public information campaigns
- Relatives or carers
- Friends or acquaintances
- Patient organisations
- Medical professionals (e.g. doctors, nurses)
- Pharmacies
- Commercial companies
- “Dr Google” (searching the Internet)
- Specialised websites with healthcare advice
- Newspapers
- TV or radio
- Patient education programmes or “patient academies”
- Other (please specify):

III. Your experience on quality of care

13. * Your answers to this questionnaire were based mostly:

- On your personal experiences
- On the experiences of your relatives or friends
- On the experiences of (members of) your patient organisation
- Other (please specify)

14. How many times have you interacted with the healthcare system in the past 12 months?

- 1-4 times
- 5-10 times
- 11 times or more
- None

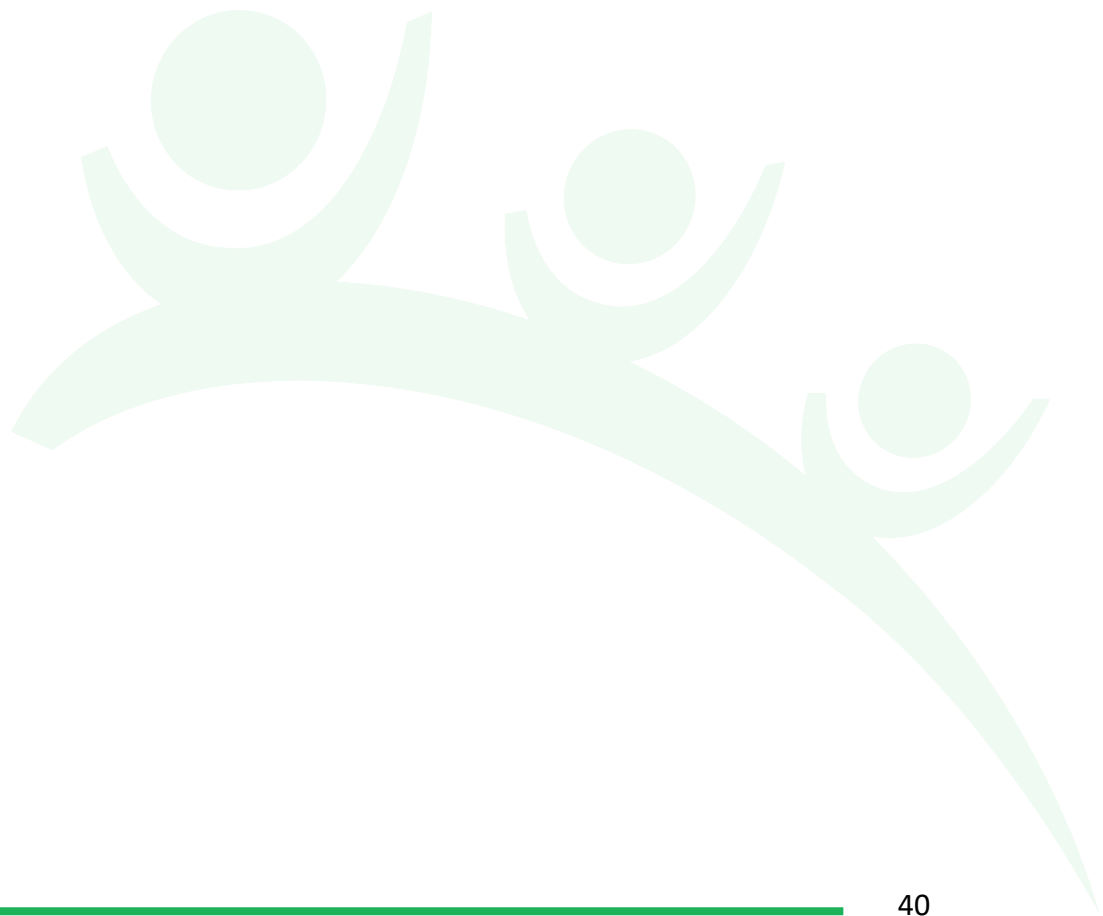
15. How would you evaluate the quality of healthcare offered to you in the past 12 months?

- Very good
- Good

- Acceptable
- Bad
- Very bad
- Variable
- I have not used healthcare services in the past 12 months

Please provide comments, if you wish:

16. What is the main change you would like to see happening in order to improve the quality of healthcare? Please describe in your own words.
17. *Would you like to be contacted for an interview on the quality of healthcare in the next months?
 - No, I prefer not to be contacted.
 - Yes, you can contact me. (Please provide your name and email address):
18. Please add any comments which will help us understand better your answers to this questionnaire:



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