

Access to healthcare

EPF's survey – final report

16/12/2016



Acknowledgments

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Executive summary

The EPF survey on access to healthcare is the first survey launched by the European Patients' Forum to gather knowledge on the experience of patients with chronic and long term conditions and family carers on access to healthcare across the European Union and across conditions. The objective is to identify potential challenges or good practices in the area of access to healthcare for patients, to inform policy making and ensure that responses to access challenges are developed with consideration of the specific needs of patients with chronic and long term conditions.

METHODOLOGY

The survey questionnaire was shaped with input from patients' organisations and patient representatives, to ensure that the questions encompassed the main dimensions of access to healthcare that are important to patients. The main dimensions used in this survey, namely availability, affordability, adequacy, accessibility and appropriateness were previously discussed as part of the EPF position paper on defining access from the patients' perspective (2016).¹ The survey was carried out online through Survey Monkey®. EPF received 395 responses from 28 EU Member States between 9 August 2016 and 31 October 2016. The survey was specifically aimed at patients with chronic and long term conditions and/or their informal and family carers.²

KEY FINDINGS

The patients' perspective on access to healthcare collected through the survey provides important insight on health inequalities and access barriers met by patients with chronic conditions within the European Union. It confirms that access to healthcare is a complex and multi-dimensional issue.

1. Information on available healthcare is lacking, and its quality needs to be improved

More respondents indicated dissatisfaction with information on available healthcare than those indicating the contrary. Patients dissatisfied indicated lack of transparency on the cost

¹ [http://www.eu-](http://www.eu-patient.eu/globalassets/policy/access/epf_position_defining_and_measuring_access_010316.pdf)

[patient.eu/globalassets/policy/access/epf_position_defining_and_measuring_access_010316.pdf](http://www.eu-patient.eu/globalassets/policy/access/epf_position_defining_and_measuring_access_010316.pdf)

² A carer as a person who provides unpaid care to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal framework (Eurocarers, <http://www.eurocarers.org/>, retrieved 2 April 2013). From EPF's point of view, the notion of informal carers is intended to indicate families, relatives and friends of a patient.

of healthcare, lack of availability of information that is easy to understand, and difficulties in accessing such information as the most prominent gaps and hurdles. This lack of communication and of quality information on available healthcare is a potential barrier to access.

2. Too many patients in the EU are confronted with financial hardship as a result of healthcare costs

The survey confirms that a large group of patients are facing financial hardship as a result of their healthcare costs. About 60% of respondents have faced financial difficulties at least sometimes as a result of spending on healthcare. For many of these patients, this means reducing spending on some essential needs such as food or clothing, and/or postponing healthcare visits or treatment. Postponing seeking healthcare can result in complications, hospitalisations and worse health outcomes and ultimately more costs for both patients and the healthcare system.

3. Some patients meet significant delays in accessing key services, in particular specialist care and diagnostics tests

Most respondents indicated that they face no significant delays in access to most essential health services or products (medicines, medical devices or equipment, intervention or treatments, appointments with a nurse or primary care doctor, support from social services, diagnostic tests) with the exception of appointments with a specialist. However, one fifth of respondents indicated facing such delays for almost all services listed. With regards to access to diagnostic tests: two fifths of respondents indicated delays.

4. The safety and quality of healthcare in the EU is unequal, and key aspects of patient-centred healthcare are not implemented

Responses to questions assessing quality and safety of care, including the patient-professional relationship indicate very split results, which suggests both good and bad practices exist within Europe. Respondents more often indicated that healthcare professionals only 'sometimes' adapt patients' care to their changing needs. They also indicated more frequently than other options that healthcare professionals 'never' capture their feedback on quality of care, illustrating that patients could be an untapped resource when it comes to evaluating and improving quality of care.

5. A majority of patients and informal carers are reporting experience of stigma while seeking or receiving healthcare

Most respondents reported that they had experienced stigma when seeking or receiving healthcare. Among those who reported such an experience, the stigma was often on the basis

of their chronic conditions, indicating that health status/chronic condition can potentially be a ground for stigma or discrimination although it is not always recognised as such in legislation to tackle discrimination. The main challenge that was indicated by respondents is the attitude of healthcare staff, and most respondents indicated that education of healthcare staff is the essential area to focus on in order to prevent the occurrence of stigmatising experiences.

6. Patients with multimorbidities and patients with lower income are more vulnerable to the risk of meeting barriers in accessing healthcare

Comparison of data shows that patients with multimorbidities have a more negative experience with respect to various aspects of access (specifically affordability and accessibility) than patients with one chronic condition. For respondents having assessed that they had some degree of difficulty to make ends meet with their income, affordability was also a stronger issue than for respondents having assessed that they could make ends meet with some degree of ease. Respondents with lower income also indicated a somewhat more negative experience in all other dimensions of access.

7. Respondents from Member States that joined the EU after 2004 tend to experience more significant challenges in various dimensions of access than respondents from Member States having joined the EU prior to 2004.

Patients from EU Member States having joined the EU after 2004, indicated having experienced more difficulties with various aspects of healthcare including affordability, adequacy and appropriateness (more experience of stigma) than patients from Member States having joined the EU prior to 2014. However, further in depth research is needed to provide a more specific picture of the differences between various regions of the European Union, and in particular to understand the impact of different welfare systems on access to healthcare for patients with chronic diseases.

8. The survey indicates divergent experiences as to access to healthcare across the European Union

Results for various questions do not illustrate important similarities in responses, which seems to indicate that patients face very different experiences when accessing healthcare in the European Union. Responses to open ended questions tend to confirm this finding and also indicate that barriers to healthcare access are diverse and varied across and within EU Member States. The main issues identified by participants differ from one Member State to the other.

POLICY RECOMMENDATIONS

This report identifies several areas of action for decision makers at EU and national level to address in order to ensure patients with chronic conditions have access to high quality, affordable healthcare across the European Union. While there is no one size fits all solution, since access issues can differ within and between Member States, throughout the survey some recurring issues are identified by patients where the European Union could have a key supporting role.

1. Ensuring affordability of healthcare

Responses demonstrate that a combination of measures is necessary in order to address the important obstacles patients' face in relation to affording healthcare:

- Measures to ensure appropriate support and appropriate healthcare coverage for patient groups most vulnerable to financial hardship as a result of healthcare costs (e.g. patients with low income, with multimorbidity).
- More transparent information on the basket of care covered and reimbursed.
- Meaningful patients' organisations involvement in the decision making processes of what services are covered as part of the basket of care, in order to ensure that important services are not left out, and that chronic conditions are appropriately recognised by the healthcare system.
- EPF also recommends to put in place an appropriate strategy in order to address the issues highlighted as regards access to innovative medicines (high prices, shortages, long delays).

2. Tackling organisational challenges

Organisational changes are needed in EU healthcare systems to ensure timely access to specialist healthcare professionals, to improve patient centeredness of care, to ensure the package of services covered by the healthcare system is tailored to the need of patients with chronic and long term conditions and to promote better coordination and delivery of care.

In addition, training of healthcare professionals on chronic, long term and rare conditions, on communication with patients and on human rights have also been flagged as essential in order to provide a higher quality of access to healthcare.

3. Ensuring appropriate resources are invested efficiently and sustainably in healthcare

Lack of appropriate resources or inefficient investment in healthcare systems were identified by some participants as a fundamental issue in their countries. Cuts in healthcare budgets and increase in co-payments should be assessed carefully as they have a negative impact on patients. Appropriate resources have to be allocated to hire and retain healthcare

professionals in order to solve the challenge of waiting times, which was identified as a key concern for some respondents.

Another source of waste of resources is corruption. Further actions are needed both by Member States affected and by the European Union to monitor, take action to sanction corruption and solve this issue that is an obstacle to patients' access to healthcare.

4. Recognising patients are part of the solution and ensuring patients' perspective on access to healthcare is collected and used

As the survey demonstrates, patients with chronic and long term conditions have valuable experience as a result of their interaction with the healthcare system and can identify important gaps and propose solutions in order to improve access to healthcare. Capturing feedback from individual patients and ensuring their collective input through patients' organisations needs to be appropriately taken into account in decisions that affect access to healthcare.

List of acronyms

EC – European Commission

EPF- European Patients' Forum

EU – European Union

R&D – Research and Development

WHO – World Health Organisation

UN – United Nations

SDGs – Sustainable Development Goals

NGOs – Non Governmental Organisations

Introduction

WHAT IS EPF?

The European Patients' Forum (EPF), which designed and carried out this survey, is an EU umbrella organisation that works with patients' groups in public health and health advocacy across Europe. EPF's membership is made up of European chronic disease-specific groups and national patient coalitions.

EPF's vision is that all patients with chronic and/or lifelong conditions in the EU have access to high quality, patient-centred equitable health and social care.

EPF'S VISION ON ACCESS

Patients' access to equitable and quality healthcare is a key priority for EPF, as highlighted by the second goal of our strategic plan 2014-2020³:

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.

Health equity is also part of EPF's core values: we believe that every patient should have equitable access to patient-centred high-quality health and social care. We strive to fight the disparities existing within the EU in relation to access to and standards of care for chronic diseases and/or long-term conditions.

Breaking down access barriers was at the heart of the EPF campaign during the 2014 EU elections, aiming to ensure that EU institutions raised this issue higher on the agenda for the new legislature (2014-2019).⁴ In 2017, EPF will be launching a Campaign on Access to Healthcare.⁵ Under the tagline 'Universal Health Coverage For All', the campaign will be an opportunity to raise awareness about the barriers patients face in accessing healthcare, and to build on current political momentum, including the UN sustainable development goal for health, to foster more EU cooperation on access to healthcare.

Access to healthcare is a basic human right⁶ and one of the fundamental principles of European health systems, together with safety, quality, and equity. Treatment should be accessible to every patient who needs it, not only to those who can pay. Regrettably, this is not a reality for all.

BACKGROUND INFORMATION

Disparities in access to healthcare predate the financial crisis in the EU, but against a background of austerity measures and falling healthcare spending in many Member States since 2009, inequalities have been made worse.⁷ Access to care is affected by austerity

³ <http://www.eu-patient.eu/globalassets/library/strategic-planning/epf-strategic-plan-2014-2020-final.pdf>

⁴ <http://www.eu-patient.eu/campaign/EPFCampaign2014Elections/>

⁵ EPF Campaign on Access to Healthcare, 2017 <http://www.eu-patient.eu/campaign/access-to-healthcare/>

⁶ EU Charter of Fundamental Rights, Article 35 – Healthcare <http://fra.europa.eu/en/charterpedia/article/35-health-care>

⁷ See OECD- health at a glance 2013 <http://www.oecd.org/els/health-systems/Health-at-a-Glance-2013.pdf> And Eurofound (2014), Access to healthcare in times of crisis, Publications Office of the European Union,

policies in response to the economic crisis, such as cuts in healthcare budgets and in insurance coverage, increased fees and co-payments, and cuts in social protection measures. All this comes at a time of even greater demand for healthcare and social support.

At the same time, healthcare systems are facing increasing demands as a result of demographic change. As the population ages, the number of patients with chronic diseases is growing. Many diseases become more prevalent with age and though some are preventable to some extent, others are not. Patients who developed a chronic disease at a younger age are also living longer, thanks to modern medical treatments. Patients with chronic diseases develop specific needs which the healthcare systems need to adapt to. The European Parliament noted that patients with chronic diseases “form a specific group which suffers inequalities in access to diagnosis and care, social and other support services, and disadvantages including financial strain”.⁸ This is why this survey focuses specifically on this population.

SURVEY OBJECTIVES

The EPF survey on access to healthcare aimed at capturing the insight of individual patients with chronic conditions and informal/ family carers⁹ across disease areas and EU Member States as regards various dimensions of access to healthcare and treatment.

This input is aimed to inform EPF’s policy and advocacy work on access to healthcare, including a campaign on universal access planned for 2017. The objective is to improve knowledge on access barriers and inequalities that patients and their family carers face across the European Union. Collecting the experience of patients with chronic conditions is crucial to inform policy makers at EU level to make appropriate recommendations to ensure universal access in the EU.

Luxembourg.

http://www.eurofound.europa.eu/sites/default/files/ef_publication/field_ef_document/ef1442en.pdf

⁸ <http://www.europarl.europa.eu/sides/getDoc.do?type=REPORT&reference=A7-2011-0032&language=EN>

⁹ A carer as a person who provides unpaid care to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal framework. This role is often taken on by families, relatives and friends of a patient.

Methodology

QUESTIONNAIRE DESIGN

The EPF survey questions were designed with the input of the EPF working group on access, an internal working group set up in December 2014 to advise EPF on its work on access, which includes 11 representatives from the EPF membership.¹⁰

The survey looks at 5 dimensions of access which can be summarized as follows:

- Availability – whether a healthcare service or product is available in the healthcare system of a country
- Affordability – whether seeking healthcare causes financial hardship to patients
- Accessibility– Whether there are barriers, other than financial (e.g. waiting lists, geographical barriers...), that stop patients from accessing healthcare
- Adequacy – the quality of healthcare and involvement of patients in shared decision making with their healthcare professionals
- Appropriateness – whether healthcare meets the need of different groups in the population

These 5 dimensions were identified in 2015 in a position paper on defining access from the patients' perspective.¹¹ This definition is an adaptation from definitions in scientific literature, and was adapted to the perspective of patients with chronic diseases with the help of the EPF Access Working Group and a membership consultation.¹²

The survey questions were first developed and discussed in a meeting of the working group on access. A PhD student provided pro bono advice on a first draft of the survey. It was then beta-tested by patients and patients' representatives.

DATA COLLECTION

Data collection was launched on 9 August 2016 through a message informing the EPF member organisations about the survey available on the Survey Monkey® webpage. The deadline for

¹⁰ <http://www.eu-patient.eu/About-EPF/workinggroups/working-group-on-access-to-healthcare/>

¹¹ [http://www.eu-](http://www.eu-patient.eu/globalassets/policy/access/epf_position_defining_and_measuring_access_010316.pdf)

[patient.eu/globalassets/policy/access/epf_position_defining_and_measuring_access_010316.pdf](http://www.eu-patient.eu/globalassets/policy/access/epf_position_defining_and_measuring_access_010316.pdf)

¹² 9 Penchansky R, Thomas JW "The concept of access: definition and relationship to consumer satisfaction" Med Care. 1981 Feb; 19(2):127-40. <http://www.ncbi.nlm.nih.gov/pubmed/7206846/> Patient access partnership (PACT)definition: http://www.eupatientaccess.eu/page.php?i_id=19

respondents to provide their input was 31 October 2016. Reminders to complete the survey were sent to EPF member organisations through targeted email, internal and external newsletters and social media reminders. The data collected was analysed in November and December 2016.

ETHICAL CONSIDERATIONS

Aspects such as confidentiality and anonymity were considered; respondents were informed about their confidentiality and anonymity in the introduction of the survey. When completing the survey, the respondents were informed about providing their consent concerning the use of the survey results for EPF advocacy on access to healthcare. In the survey, respondents were asked to provide contact details for the purpose of follow up interviews. Providing such contact details was optional. Demographic information from respondents is presented in such a way that no link can be established between the person who reported data and the information provided.

DATA ANALYSIS

The data analysis was performed through Survey Monkey® and Excel. The two tools were used complementarily to increase the robustness of the findings which served to formulate recommendations.

The database of survey responses in Survey Monkey® was cleaned by removing the incomplete ones. The results from the final 395 completed surveys were exported to an Excel database where data analysis was performed, including re-categorising of some answers. Statistical analysis was done using the Survey Monkey® software.

LIMITATIONS OF THE SURVEY

The survey focused on the opinion of respondents who volunteered to take the questionnaire, which comprised patients with chronic or long term conditions, and informal/family carers. No statistical conclusion can be made regarding the results and opinion of the entire patients' community.

One limitation noted by participants is that the survey was only carried out in English. This impacted negatively on the number of responses received from countries where English is not the native speaking language. Another limitation is that the survey was carried out online, which could also have excluded some patients or informal carers who have no access to internet. In order to receive more responses from individual patients and informal carers, translation of surveys on access to healthcare in several or all EU languages should be considered in the future.

Though effort was made to make questions and pre-defined answers comprehensive, notably through the drafting of the survey with patients and patients’ representatives through the EPF Access working group and beta-testing, the pre-defined answers can be viewed as limiting with regards to response possibilities. To address this, various open-ended questions were included to provide opportunities for respondents to address issues not covered in the pre-defined answers.

Although efforts were made to make the sample representative and to ensure representation from 28 Member States, the sample collection methodology means that some vulnerable groups of patients may not have been included or may be underrepresented in the sample of respondents. This may be the case, for example, for undocumented migrants, homeless people or disabled people. However, the fact that the majority of respondents experienced barriers in access to healthcare would suggest that the situation would be similar or worse for patients with chronic and long term conditions who belong to a vulnerable group. However, more research would be required to capture the perspective of patients from various vulnerable groups on access to healthcare in the EU.

Results

GENERAL INFORMATION REGARDING THE RESPONDENTS

The 395 completed surveys were submitted by 209 patients with a chronic or long term condition, 116 patients with several chronic and long term conditions, 56 family members/informal carers and 14 patients who are also informal carers.

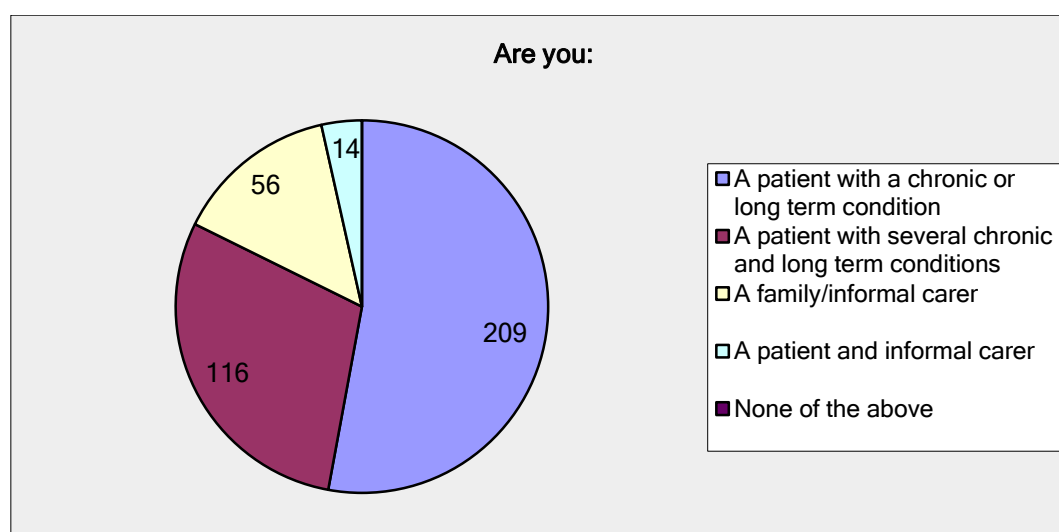


Figure 1. Status of survey respondents (4 pre-defined answers)

The **age category** of respondents (or age of patient responding on behalf of) varied greatly across the respondents, with the spread of age in the survey goes from age 5¹³ to age 90. Six people did not respond to this question.

The table with the age categories of participants is included below:

| What is your age? * | |
|---------------------|----------------|
| Answer Options | Response Count |
| 17 or younger | 25 |
| 18-20 | 7 |
| 21-29 | 50 |
| 30-39 | 78 |
| 40-49 | 96 |
| 50-59 | 72 |
| 60 or older | 61 |

Table 1. Age of respondents (*or age of patient you are responding on behalf of)

Concerning the **gender of participants** in the survey, 88 men completed the survey, while the number of responding women was 299. 3 respondents were transgender and 2 preferred not to answer the question. Three respondents did not complete this question.

¹³ It was possible for family carers to reply on behalf of a patient, which explains the younger age bracket

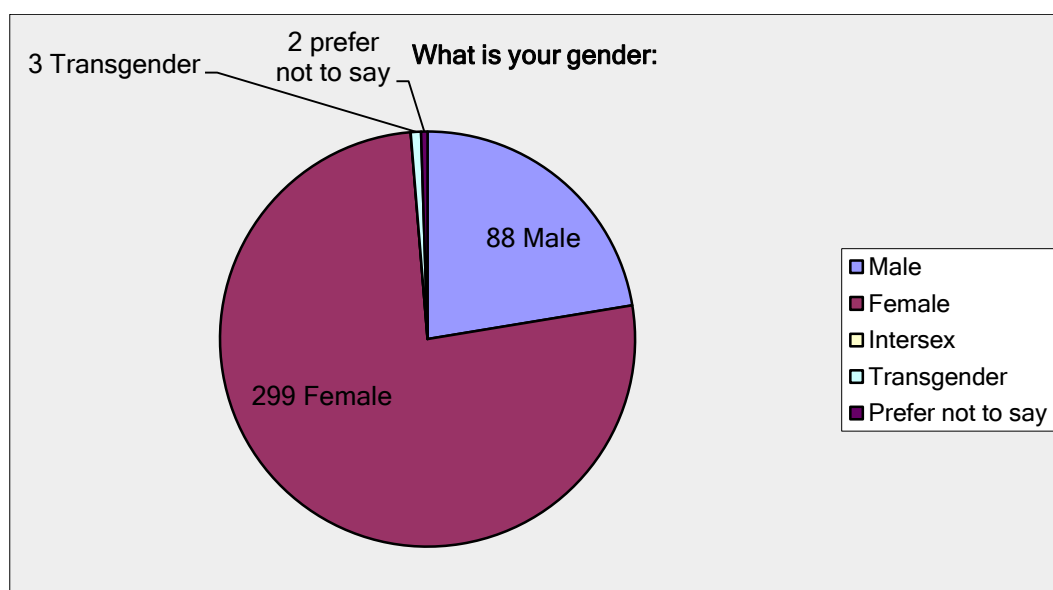


Figure 2. Gender of survey respondents (4 pre-defined answers)

Distribution of respondents per country varied greatly in terms of the number of completed surveys. The highest number of surveys were completed by respondents from the United Kingdom (42), followed by Finland (35), Sweden (29), and Latvia (24).

The table below only presents countries that were mentioned in response to this question.

| Your country of residence is: | | |
|-------------------------------|------------------|----------------|
| Answer Options | Response Percent | Response Count |
| Austria | 3.1% | 12 |
| Belgium | 3.1% | 12 |
| Bulgaria | 4.6% | 18 |
| Croatia | 2.3% | 9 |
| Cyprus | 3.1% | 12 |
| Czech Republic | 1.8% | 7 |
| Denmark | 4.9% | 19 |
| Estonia | 1.0% | 4 |
| Finland | 9.0% | 35 |
| France | 2.6% | 10 |
| Germany | 3.1% | 12 |
| Greece | 2.8% | 11 |
| Hungary | 3.3% | 13 |
| Ireland | 4.9% | 19 |
| Italy | 3.1% | 12 |
| Latvia | 6.1% | 24 |

| | | |
|--------------------------|-------|------------|
| Lithuania | 1.8% | 7 |
| Luxembourg | 0.5% | 2 |
| Malta | 2.0% | 8 |
| Netherlands | 3.6% | 14 |
| Poland | 1.8% | 7 |
| Portugal | 4.6% | 18 |
| Romania | 2.6% | 10 |
| Slovakia | 1.5% | 6 |
| Slovenia | 2.8% | 11 |
| Spain | 2.0% | 8 |
| Sweden | 7.4% | 29 |
| UK | 10.7% | 42 |
| answered question | | 391 |
| skipped question | | 4 |

Table 1. Distribution / country of respondents

The overwhelming majority – 75% - of respondents live in an urban area (defined as a city, a city suburb, or a medium to large town) as opposed to a rural area (defined as open countryside or a village/small town).

When asked how easy it is for their household to make ends meet with their total monthly income, the responses were split fairly evenly between ease and difficulty.

| Answer Options | Response Percent | Response Count |
|--------------------------|------------------|----------------|
| Very easily | 9.4% | 37 |
| Easily | 17.0% | 67 |
| Fairly easily | 24.6% | 97 |
| With some difficulty | 27.7% | 109 |
| With difficulty | 12.2% | 48 |
| With great difficulty | 5.6% | 22 |
| Don't know | 1.3% | 5 |
| Prefer not to say | 2.3% | 9 |
| answered question | | 394 |
| skipped question | | 1 |

Table 2. Difficulty/Ease to make ends meet with household income

AVAILABILITY

For EPF, the availability component aims at assessing whether healthcare services or products are available to the patient in the healthcare system of Member States in the first place.

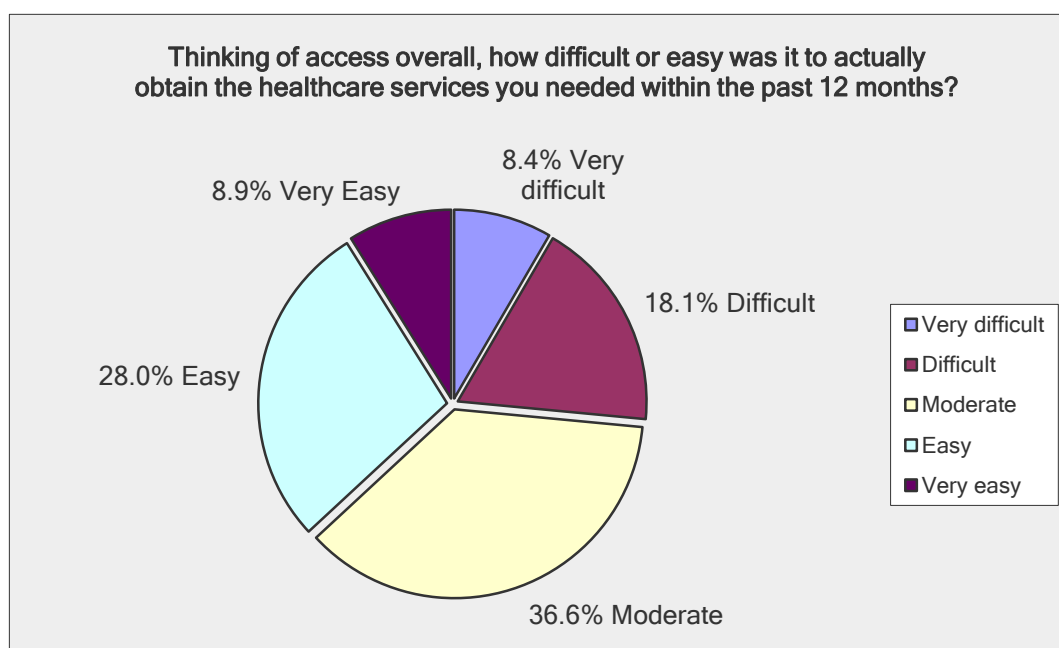


Figure 3. Overall ease of access (5 pre-defined answers)

When asked, overall, **how easy or difficult it is to obtain healthcare services they need**, 36.9% of patient indicate it is easy or very easy, 36.6% indicate a moderate ease of access, while 26,5% indicate it is difficult or very difficult, showing respondents were divided on this question.

EPF also asked questions regarding the availability of information on healthcare services, as this was indicated by members as important in order to access healthcare.

When asked to rate **different sources of information on healthcare**:

The following sources were regarded as providing good quality information by the highest percentage of respondents: Internet websites (69%), patient organisations (68%), doctor's practice (46%), relatives and peer patients (44%) hospital (41%), pharmacies (40%), social media (41%),

The following sources were regarded as providing rather average quality information by the highest percentage of respondents: public health authorities (36%)

The following sources were regarded as providing poor quality information by the highest percentage of respondents: school (39 %), work (44%), television (47%), health insurances (47%)

When asked about **information on available healthcare**:

- It is not easy to find according to 46.49% of respondents, while 36.88% perceived it is easy to find

- It is not easily accessible for people with disabilities according to 56.75% of respondents, while 19.79% found it accessible for people with disabilities
- It is not easy to understand according to 52.74% of respondents, versus 27.42% who find information easy to understand
- It is useful according to 51.16% of respondents, versus 23.51% who declared it is not useful
- It is not transparent on the financial (out-of-pocket) costs for the patients according to 47.1% of respondents, versus 21.04% who answered it is transparent

AFFORDABILITY

This part of the questionnaire aimed at assessing whether healthcare is affordable for patients, or if the costs of healthcare causes them financial hardship.

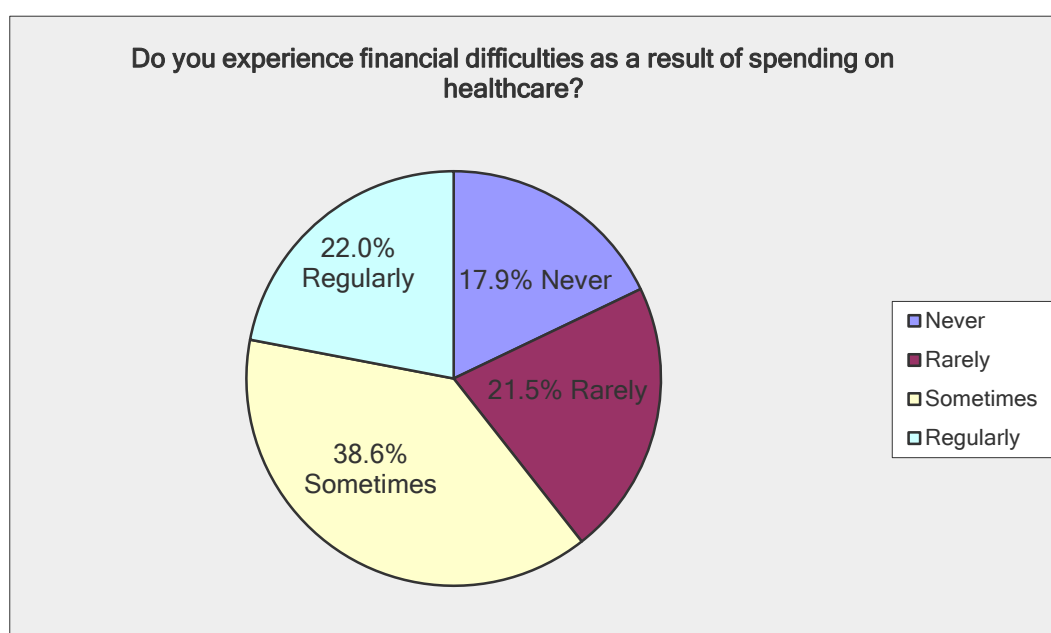


Figure 4. Financial difficulties (4 pre-defined answers)

As shown in Figure 4, 50.6% of participants indicated experiencing **financial difficulties as a result of spending on healthcare** at least sometimes. Among these, 22% declared that it caused financial difficulties regularly.

When asked more specific questions about their **ability to afford specific services when needed**, responses varied very importantly depending on the service concerned.

For primary care doctors approximately 57% of respondents declared they can always afford the cost, while results indicated 38% for specialised doctors, 22% for specialised healthcare professionals such as physiotherapist or psychologist. 45% of respondents declared they can

always afford hospital costs when they need it, 41 % declared they can always afford the cost of their medicines when needed, 24% for medical equipment, 25 % for dental care, and 10% could always afford reconstruction or cosmetic intervention necessary as a result of their diseases when they need it.

41% of respondents reported **reducing household spending on essential needs, such as food or clothing**, to be able to cover healthcare costs, while 59% responded they did not need to reduce such spending on essential needs such as food or clothing.

40% of respondents reported **forgoing or postponing healthcare visits because of costs in the past 12 months** at least one time. Among these, 14% said they did so 3 times or more. The majority of respondents (60%) indicated they never postponed healthcare visits because of costs.

A similar question was asked regarding **forgoing/postponing healthcare treatment because of cost in the past 12 months**. 64 % of respondents did not forgo or postpone treatment, while 36% did it at least once and amongst this 13% did it at least 3 times.

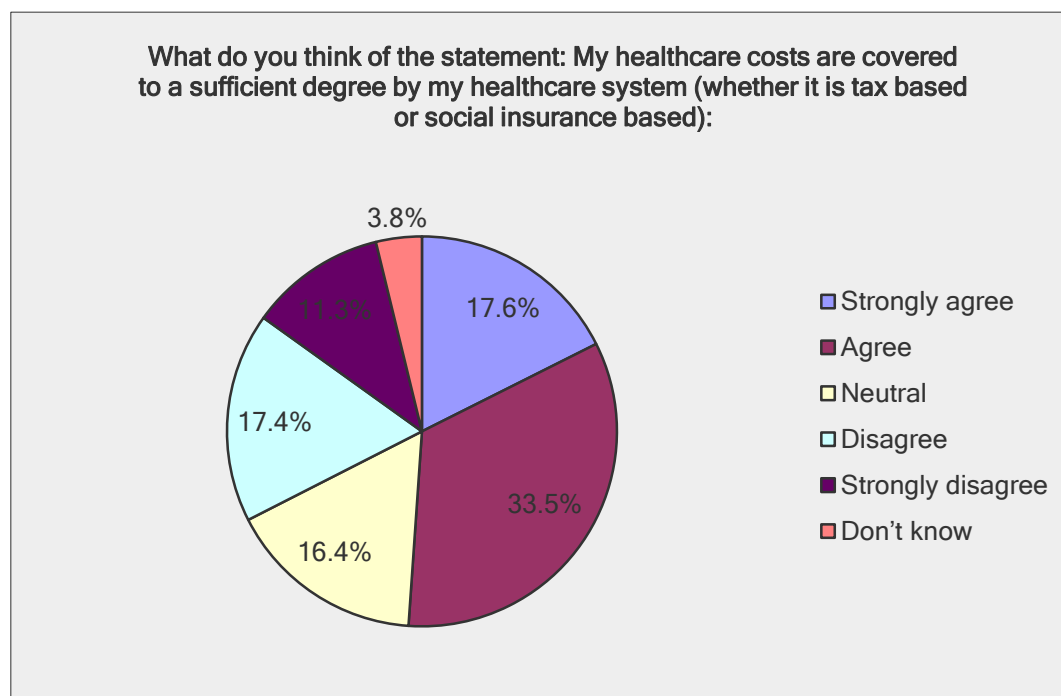


Figure 5. opinion on coverage of healthcare cost (6 pre-defined answers)

As shown in Figure 5, when asked if their **healthcare costs are sufficiently covered by their healthcare system**, participants answered that they agreed or strongly agreed at 51.1 %, while 16.4% participants stayed neutral and 28.7% disagreed or strongly disagreed.

36.5 % of respondents indicated that they need to have recourse to a **private or complementary healthcare insurance** to cover their costs.

When asked for further comments on **healthcare coverage** (open question), 101 respondents provided comments. Some respondents indicated their satisfaction with their current coverage. Some of these respondents noted that in the public healthcare system of their country which provides care at an affordable cost, the main issue is waiting times, which sometimes means patients need to have recourse to private healthcare at their own cost in order to receive timely care.

The majority of respondents made comments indicating **unmet needs**.

- A few respondents noted that some parts of their healthcare needs are not currently covered, such as dental care services or physiotherapy. They also need to pay out-of-pocket for necessary items or nutritional complements prescribed by the healthcare team (e.g. sunscreen for patients with Lupus etc.)
- Other respondents indicated facing important barriers due to their healthcare coverage and expressed the difficulties they face to afford their treatment.
- Another group of respondents indicated that while healthcare is generally affordable, appropriate care, recognition or appropriate medication for their specific conditions are not available in their country.

Below are some quotes of patients related to healthcare coverage:

"There are very expensive medicines uncovered by insurance, for melanoma patients... and others." - A family carer from Romania

"What is available on the state healthcare system and what needs complementary health insurance is utterly confusing and no free advice is available" - A patient from the UK

"In my case, most of the medicines and specialists' visits are free due to the state system in Malta." - A patient from Malta

"In Italy my disease, Systemic Sclerosis, is not recognised as rare disease. We've been waiting for too many years! This would mean less money to cover healthcare costs." - A patient from Italy

"I have to buy all my life support medications (for kidney transplant and others) if I want to live!" - A patient from Bulgaria

"Some costs are covered by the public system such as visits to the rheumatologist. While I was waiting to see the rheumatologist there were multiple trips to the GPS and Physio which I had to cover the cost of myself." - A patient from Ireland

"If I weren't in such a good financial state, it would have been much worse because most of the healthcare is done privately due to long queues in public healthcare system or insufficient programs (for example physiotherapy)" - A patient from Poland

"I don't have a private or complementary health insurance because they are too expensive and do not cover chronic diseases which amount the most for the total cost of care in our household." - A patient from Portugal

"In Latvia, government pays for many services, and, if you are lucky enough to get them, it's just about 4 euros per visit at doctor/specialist. The problem is huge waiting times, which push people to choose self-paid visits (which is then 20-25-35 euros, and many state paid services are denied for such visits - like lab tests, etc.)" - A patient from Latvia

"I am over the eligibility limit to qualify me for a medical card so I have to pay for all my healthcare and dental costs but my salary is insufficient to cover all the costs. On top of this I have to pay for private medical insurance to avoid very lengthy waiting lists in the public healthcare system and pay for private services unavailable in the public healthcare system" - A patient from Ireland

ACCESSIBILITY

The accessibility part of the questionnaire aimed at assessing whether respondents encounter barriers, other than financial (e.g. waiting times, geographical barriers...), that stop or delay their access to healthcare.

| Over the past 12 months, have you experienced a significant delay in accessing: | | | | |
|---|-----|-----|----------------|----------------|
| Answer Options | Yes | No | Not applicable | Response Count |
| Your medicine(s) | 79 | 282 | 29 | 390 |
| A treatment intervention, such as surgery or other procedure. | 95 | 188 | 104 | 387 |
| A medical device or medical equipment | 65 | 181 | 140 | 386 |
| A diagnostic test | 143 | 203 | 42 | 388 |
| An appointment with a nurse | 56 | 215 | 114 | 385 |
| An appointment with a primary care doctor (e.g. a general practitioner) | 94 | 263 | 31 | 388 |
| An appointment with a specialist | 197 | 165 | 26 | 388 |
| Help/support from social services | 84 | 100 | 201 | 385 |
| <i>answered question</i> | | | | 390 |
| <i>skipped question</i> | | | | 5 |

Table 3. Significant delays in accessing services (3pre-defined answer)

When asked if they experienced **delay in relation to accessing various services** respondents indicated:

- 72% did not experience delay in access to medicines, while 20% did experience such delays
- 48% experienced no delay in accessing a treatment intervention, while 24% did experience a delay
- 47% experienced no delay in accessing a medical device, and 17% did
- 52% experienced no delay in accessing a diagnostic test, while 37% did
- 56% experienced no delay in accessing an appointment with a nurse 14% did
- 68% experienced no delay in accessing an appointment with a primary care doctor, while 24% did
- 50% experienced a significant delay in accessing appointments with a specialist, while 42% did not
- 26% did not experience any delay in accessing support from social services, while 20% did

| Would you say the following services are located near enough from your home? | | | | |
|--|-----|-----|--|----------------|
| Answer Options | Yes | No | | Response Count |
| A pharmacy | 380 | 9 | | 389 |
| A GP | 345 | 39 | | 384 |
| A specialist | 266 | 123 | | 389 |
| An hospital | 307 | 82 | | 389 |
| <i>answered question</i> | | | | 390 |
| <i>skipped question</i> | | | | 5 |

Table 4. Geographical accessibility of services (2 pre-defined answers)

As shown in Table 4, **accessibility to various services in terms of geographical distance from home** was usually thought to be good for most services, with a somewhat more significant gap for access to a specialist where 123 out of 390 respondents felt they were not located near enough from their home.

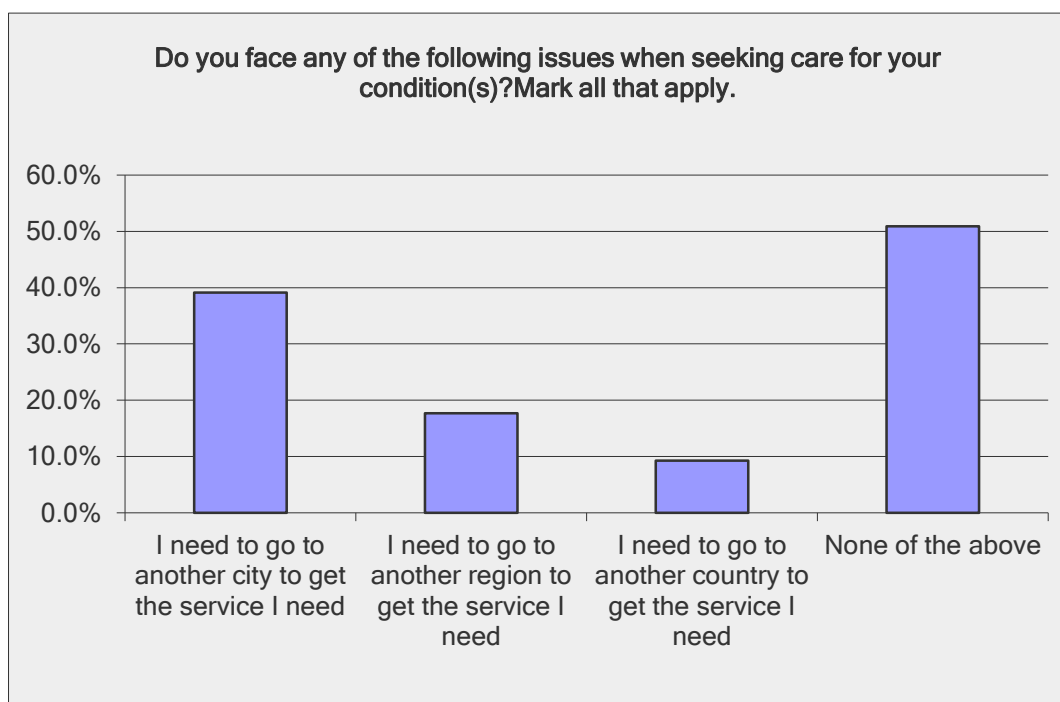


Figure 6. Seeking healthcare in different city, region or country (4 pre-defined answers)

As indicated in Figure 6, 39.1% of respondents need to travel to another city to get the service they need, 17.7% need to go to another region and 9.36% need to go to another country. About half of the respondents (50.9%) indicated they do not need to travel when seeking healthcare for their conditions.

ADEQUACY

This part of the questionnaire related to quality of care, and in particular the quality of the patient-healthcare professional relationship and the involvement of patients in shared decision-making regarding their treatment.

To that end, respondents were asked to rate a series of statements on a scale comprising 5 answers (always, very often, sometimes, rarely, never).

The first series of statements focused on **patient-healthcare professional communication**:

- When asked if they were adequately informed by their healthcare providers about treatment options: 16.54% replied always, **32.56% replied very often**, 31.78% replied sometimes, 12.66% replied rarely and 6.46% replied never.
- When asked if they were involved in decisions regarding their care by healthcare providers: 25.32% replied always, **30.49% replied very often**, 27.13% replied sometimes, 11.89% replied rarely and 5.17% replied never.
- When asked if their healthcare provider provides the information they need regarding safety of their treatment: 21.19% replied always, 28.94% replied very often, **29.46% replied sometimes**, 13.44% replied rarely and 6.98% replied never.
- Respondents were also asked if healthcare providers adapt their healthcare to their changing needs: 20.16% replied always, 27.91% replied very often, **29.20% replied sometimes**, 15.5% replied rarely and 7.24% replied never.
- Finally, when asked whether their healthcare providers are capturing their feedback on the quality of care provided to them: 9.95% of respondents replied always, 14.92% replied very often, 22.25% replied sometimes, 23.30% replied rarely and **29.58 % replied never**.

A second series of statements focused on **quality of care and safety**:

- When asked if they receive good quality care according to the standard/ guidelines or best practices available for their condition, **52.36% indicated that it was the case at least very often or always**, 27.84% indicated it is sometimes the case, while 16.34% felt it is rarely or never the case, and 3.6% did not know.
- When asked if they were satisfied with the safety of care provided to them, **54.90% indicated that it was the case at least very often or always**, 24.48% indicated it is sometimes the case, while 17.53% felt it is rarely or never the case, and 3.1% did not know.
- Participants were also asked about their satisfaction as to the continuity of their care over time **46.13% indicated that it was the case at least very often or always**, 25.77%

indicated it is sometimes the case, while 26% felt it is rarely or never the case and 2% did not know.

APPROPRIATENESS

This last section of the survey deals with whether healthcare is appropriate to the needs of different groups of the population.

Participants were asked whether they **ever felt stigmatised when seeking or receiving healthcare on a number of grounds or characteristics** (multiple choices were possible). 46.79% declared they have never felt stigmatised in the healthcare environment, while other respondents did, in the following proportions:

- Young age: 18.51 %
- Older age: 6.68%
- Physical disabilities: 12.34%
- Intellectual disabilities: 4.88%
- Mental health status: 9%
- chronic/long term condition: 36.76%
- Ethnicity: 2.06%
- Being a woman: 12.34%
- Being a man: 1.03%
- Being intersex: 0.51%
- Being transgender: 1.29%
- Income/social status: 9%
- Religion: 0.51%
- Sexual orientation: 1.80%
- 5.91 %: Participants also felt discriminated against on other grounds including nationality, obesity, perceived lack of competence of the patient, or being perceived as a demanding patient, having an invisible condition (not looking sick).

| What type of stigma or discrimination did you experience? Mark all that apply. | | |
|--|------------------|----------------|
| Answer Options | Response Percent | Response Count |
| Attitude of healthcare staff | 64.3% | 166 |
| Denial of my rights | 23.3% | 60 |
| Inappropriate language | 19.4% | 50 |
| Lack of healthcare facility in my community | 22.9% | 59 |
| Refusal to provide me with treatment | 22.1% | 57 |
| Other (please specify) | 18.2% | 47 |
| answered question | | 258 |
| skipped question | | 137 |

Table 5: forms of stigma experienced (6 pre-defined answers)

As a follow up question, respondents were asked about **the type of stigma or discrimination they experienced** (it was possible to select several answers). In most cases, respondents highlighted the attitude of healthcare staff as the issue, and around 20 percent experienced different issues: denial of rights, lack of healthcare facility in their community, inappropriate language and refusal to provide treatment.

Respondents also highlighted other issues as part of the other category which mostly relates to making wrongful assumptions about the patient, e.g. thinking that physically disabled persons are always mentally disabled, or that a sexual orientation is a mental illness diagnosis, not believing the patient, or neglecting to provide quality of care. A small proportion of the “other” category (16 respondents) indicated they never experienced stigma.

Respondents who did encounter stigma were then asked their opinion regarding **what measures should be taken to prevent the occurrence of a similar situation in the future** (open-ended question): 119 respondents provided an answer to this question.

Most of the responses highlighted the need for education and training for healthcare professionals and staff in healthcare organisations to improve their communication with patients, ensure they take into account the patients’ perspective and listen, establish mutual trust and respect, that patients’ rights are respected and to place the needs of the patients at the centre.

A few responses focused on the need to take seriously into account young patients and to improve knowledge amongst healthcare professionals about the fact that young people can have a chronic condition. Some responses focused on appropriate training as regards behaviour with LGBTI patients, and recommended ensuring the needs of the patient comes first, before the personal values of the healthcare professional.

Another group of responses focused on the need for better medical training and awareness on specific conditions, and in particular as regard rare conditions.

Other responses called for wider change in the healthcare system: decentralisation, having standards of care and following them (but at the same time flexibility when the situation of the patient differs from the guideline), more funding for the care and support of patients with chronic diseases, hiring more healthcare professionals, improving their working conditions and ensuring they have more time for the patient.

Below are some quotes of patients regarding their ideas on how to prevent stigma

“Attend to the patient’s needs, providing me with the treatment that I need, not looking first at the costs.” - A patient from Portugal

“Increasing of competences of healthcare staff and possibility of anonymous complaints to some commission of healthcare providers.” - A patient from Croatia

“We should focus more on the education of medical staff to communicate with the different patients so they will not feel threatened, unsafe or misunderstood.” - A patient from Latvia

“Specialists need to understand that most likely we waited months for an appointment and it's upsetting when they brush you off or make you feel you do not have the right for treatment.” - A patient from the UK

“Health communication training, motivational interview for medical staff, periodical psychiatric evaluation for medical staff, periodical up-date in medical staff training regarding medicine, preventive medicine done actively, psychological services for chronic patients, more active and efficient social services.” - A patient from Romania

“Doctors and government employees needs to be more educated about the lives of chronic sick people (even regarding issues that do not show up on a test) and that we are in need of their support from time to time. They also need to understand that we want to be as healthy as we can be and that we want to try to fix what can be fixed and we need their help to do so.” - A patient from Sweden

“All medical staff needs basic education on how to deal RESPECTFULLY with transgender/intersex people, mentally ill/mentally disabled people, and people of other sexualities than straight. More of these marginalized patients should be consulted on improvement ideas, and those suggestions should reach appropriate legal bodies/ministries.” - A patient from Estonia

“Transparency, mutual respect (patients are not idiots by default, no reason to treat them childishly), all the responsibility for dealing with heavy and complex diseases is on the shoulders of GP. Few access to latest research at international level. No cooperation, for rare diseases, if there is not yet a patients’ association, we have to deal all by ourselves.” - A patient from France.

FINAL QUESTIONS

The survey concluded with two final open ended questions.

The first question related to the **participants’ opinion as to the most important action policy-makers in their country could take in relation to improving access to healthcare**. 254 respondents provided responses which can be classified in the categories below:

- A large share of respondents pointed out the **need to increase funding towards healthcare**, and/or increase resources to hire more healthcare professionals or retain them, and stop budget cuts in healthcare. A few participants also advised to improve the management of healthcare financing.
- Many respondents also called for **more affordable healthcare**, reduced co-payments, and especially measures and support to ensure people with small income have access to healthcare.
- A good share of respondents mentioned **solving organisational issues** as the priority: better access to specialists, better coordination of care, reducing bureaucracy. There were some comments regarding access to public versus private healthcare but with no consensus, and comments calling for more decentralisation and more centralisation (e.g. more or less community care, more or less big units, with no clear consensus on the preferred type of organisation.).
- Another group of respondents focused on the need for **more information to patients on healthcare and more transparency**, including more transparent information on what the healthcare system provides and on costs and quality of care, and better communication towards patients.
- **Reducing waiting times**, often combined with calls to increase the number of healthcare professionals was also an important recommendation made by many respondents.
- **Educating healthcare professionals** about chronic conditions and their impact on patients’ lives and on communication was also a recurring comment, with calls for

more training on some specialised medical topics and education on existing standards of care.

- Some comments called for **tackling corruption in healthcare systems**.
- Some comments referred to **involving patients and their organisations in decision making about healthcare**, as well as involvement of patient organisations in monitoring quality of care, and in medical research.
- A few respondents referred to **improving access to medicines** (reducing the cost or addressing parallel trade).

Below are some quotes by patients in relation to actions policy makers need to take in their countries:

“Policy makers should regularly organize meetings with the patient organizations, analyse their specific needs and seek for the best solutions together as well as to collect feedbacks from the patient organizations and health care providers too.” - A family carer from Lithuania

“Doctors and nurses should have some training and requirements on how to meet the patients. Kindness and empathy are lacking sometimes. Making a patient cry or suggesting they are pretending their illness unfortunately happens.”- A patient from Finland

“They should stop the endless cuts and should give more support. I feel I'm soon forced to use wheelchair because I can't afford all the care I needed to avoid it. Very unfair.” - A patient from Finland

“Better and clearer information about what the state healthcare provides and what it doesn't and what health insurers provide.” - A patient from the UK

“Minimise corruption in healthcare system and set up a transparency and open dialog with all relevant stakeholders (patient organisations involved). Count people as humans, not as a numbers. Take into consideration social effects of health care policies.” - A patient and informal carer from Slovakia

“Prioritizing letting poor and disabled people receive basic health care for lowest costs possible. Educating medical staff on how to ethically tend to minority patients. Preferably through practice and lectures by minority community spokespeople.” - A patient from Estonia

“Make the chroni patients not pay the most for their health care. Clear information on the costs that are now hidden given at the time that the decision on the treatment is taken.” - A patient from the Netherlands

“eliminate co-payments or adapt it balancing income/work status/ cost of the treatment. Providing mental health care beyond diagnostics and prescription. Facilitating access across autonomous regions.” - A patient from Spain

The final open ended question gave the opportunity to participants to provide any other comments regarding access to healthcare: 150 responses were provided.

Many respondents pointed out **the lack of patient centeredness in the system**. They expressed that the system is not very patient friendly or “human”, it is not easy to navigate nor centred around the users’ needs, patients are not listened to or supported, and there is lack of coordination. Some responses that illustrate this include:

“Gaining accessing to the correct medical service is difficult. Getting seen by a doctor when you need to be seen is difficult. There is a lack of information and support about options.” - A patient from Ireland

“Our healthcare system is rather complex and complicated, particularly for patients’ rare systemic diseases.” - A patient from Germany

“To me it seems extremely important the general package of services to all insured patients is tailored to their chronic/ lifelong condition if they happen to have one. People with certain conditions might need more frequently or at all some screenings, diagnostics, prevention measures, etc.” - A patient from Bulgaria

Many respondents also remarked the **lack of affordability of healthcare** and the additional barriers people with lower income face. Some of the responses that illustrate this are quoted below:

"I am a relatively mid-class person, having a good private company insurance from my employer, so I am an exception. Definitely there is no access to healthcare for people without a good insurance programme (run by a private insurance company) [...] Also many people cannot afford dental care, it is crazy expensive." - A family carer from Latvia

"We have a two tier system that is very unfair. Those who have the resources have access to quality, timely healthcare. Those in public system have access to quality care but it is not timely and it can be haphazard." - A patient from Ireland

Waiting times are once again a key issue flagged by patients:

"The queues for treatment, when it comes to specialised doctors, are unbelievable. Sometimes it takes 3 to 4 months to get your treatment." - A patient from Latvia

Various other issues are also mentioned in response to this final question, however to a lesser extent: need for better education of healthcare professionals, unequal access to quality of healthcare according to geographical distribution, with a specific issue in rural areas, lack of funding and healthcare resources, lack of access for some specific services (particularly dental care), particular difficulties to access healthcare for rare diseases. Respondents also mentioned issues around access to medicines (long access to innovation, shortages, high prices of medicines). There is also positive feedback from a small group of patients on access to healthcare in their countries (approximately 10 respondents).

"We are very lucky to have a very expensive drug which is very efficacious paid for - many other countries do not pay for this drug including my homeland (outside the EU). Therefore, I cannot go home until they start to pay (unlikely) or another cheaper drug comes to market (possible in the future as there are a number of comparators in trials)." - A patient from the UK

"I think health care in Sweden is good. However, there is a lack of education in areas such as pain disorders and chronic pain, and in the resources that health care has. They have too little time." - A patient from Sweden

“Many rare diseases have no access to health care i.e. pulmonary arterial hypertension, Fabry disease, rare oncology etc. We have no access to effective medicines, specialists, social services, disable people support, help lines, psychological support, physiotherapy, rehabilitation, lifelong services.” - A patient from Latvia

DIFFERENCES BETWEEN URBAN AND RURAL AREAS

Approximately three quarters of the respondents (75.5%) declared living in an urban area, while the remaining quarter (24.49%) declared they live in a rural area.

A comparison of the responses from these two groups of respondents does not show important differences in terms of the availability questions, which looked at overall ease of access, and information on available healthcare.

However, with regards **affordability**, when asked whether in the past 12 months they had to reduce their spending on essential needs, such as food or clothing, to be able to cover healthcare costs, 43.15% respondents from urban areas reported more often (to a small extent) that they did, while 34.38% of respondents from rural areas reported that they did.

Regarding **accessibility**, when asked about delays in accessing medicines, treatment interventions such as surgical procedures, and appointments with a specialist, respondents in urban areas reported to a small extent that they face more delays.

When asked about whether services are located near enough from their home, respondents from rural areas constantly replied yes in a somewhat less important proportion compared to respondents from urban areas, with a more significant gap when it comes to hospitals where 71.58% of respondents from rural areas declared it is near enough (versus 81.16% for urban areas), and for specialists where 53.68% of respondents from rural areas declared it is near enough (while 73.29% respondents from urban areas declared the same). A significantly wider proportion of respondents from rural areas declared that they needed to travel to another city (68.42% for respondents in rural areas, versus 29.45% for those in urban areas) or region (32.62% for respondents in rural areas, versus 13.01% for those in urban areas) to seek healthcare.

Regarding **adequacy of care**, respondents in rural areas declared to a very small extent more satisfaction in the communication with their healthcare professionals on all items (information, involvement, adaptation of care, collecting of feedback).

Regarding **appropriateness**, there was no significant variation as regard experience of stigma.

In open ended questions closing the survey, issues with regards to medical deserts, post code lottery (a situation in the UK whereby healthcare is unequal according to where the patient lives), and care being more difficult to access in rural areas were mentioned by a small number of respondents.

“Rural areas have the most problems with access. public transportation system is not well developed and travel to medical centres is not reimbursed at all.” - A patient from Estonia

PATIENTS WITH ONE CONDITION VS PATIENTS WITH SEVERAL CONDITIONS

Approximately two thirds of patients who responded to the survey indicated having one chronic or long term condition (64.3%), while one third of patients indicated they had several chronic or long term conditions (35.7%).

Comparing the responses from the two groups, the main differences can be found in the fields of affordability and accessibility.

Affordability: Patients with several chronic conditions reported somewhat more financial difficulty, with 29.31% declaring they regularly face financial difficulty due to their spending on healthcare versus 18.91% of patients with one condition declaring the same, and 50% of patients with several conditions declaring they had to reduce their spending on essential needs, such as food or clothing, to be able to cover healthcare costs in the past 12 months, versus 36.23% of patients with one condition declaring the same.

Accessibility: Patients with several chronic conditions declared to a somewhat larger extent that they face delays in accessing the following: A treatment intervention such as surgery, a medical device, a diagnostic, appointment with primary care doctors and specialists, and support from social services. When asked about geographical aspects, patients with several chronic conditions were to a small extent less satisfied as regards availability of services near their home (whether it is a pharmacy, a hospital, a specialist or a general practitioner), and indicated they had to seek healthcare in a different city or region somewhat more than patients with one chronic condition.

DIFFERENCES BY INCOME GROUPS

In this part, we compared the responses of patients who had indicated they could make ends meet very easily, easily or fairly easily (51.01%), thereafter referred to as the “easy” group, with the other group of respondents who had responded that they could make ends meet with some difficulty, with difficulty or with great difficulty (45.43%), thereafter referred to as the “difficulty” group.

As regards **availability**, when asked about overall ease of access to healthcare services within the past 12 months, significantly more respondents from the “difficulty” group reported it was difficult (21% said so versus 13% percent in the “easy” group) or moderate (43% said so versus 31% in the “easy” group). Conversely, respondents from the “easy” group responded more often that accessing healthcare services was easy (38% of them responded easy, versus 17.4% in the “difficulty” group). People from the “difficulty” income group also declared in a smaller proportion that information available about healthcare was easy to find, easily accessible for people with disability, easy to understand, useful or transparent on costs (for example 31.4% of respondents in the “difficulty” group said it was easy to find, versus 42% in the “easy” income group). Thus their satisfaction with available information on healthcare was significantly less than for the “easy” group.

Significant differences also appeared in the question under the **affordability** headline. More respondents in the “easy” group said they could always afford all of the services listed (financially) than those in the “difficulty” group. For example, for primary care doctors, 68% of respondents from the “easy” group could always afford it, while only 39.8% of the “difficulty” group replied the same.

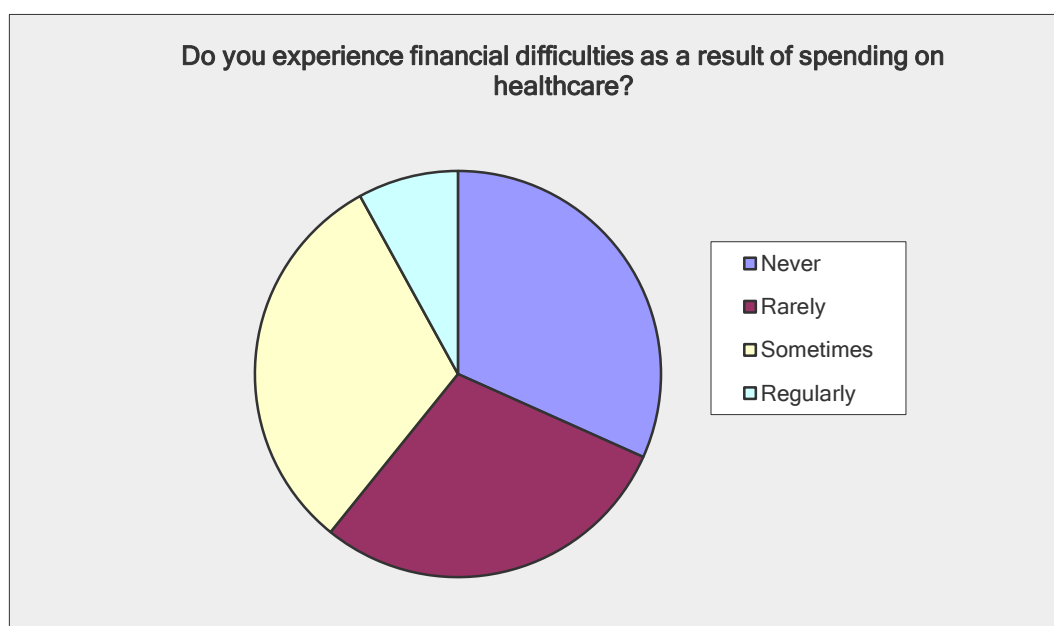


Figure 7. Experience of financial difficulties of respondents who can make ends meet fairly easily, easily or very easily

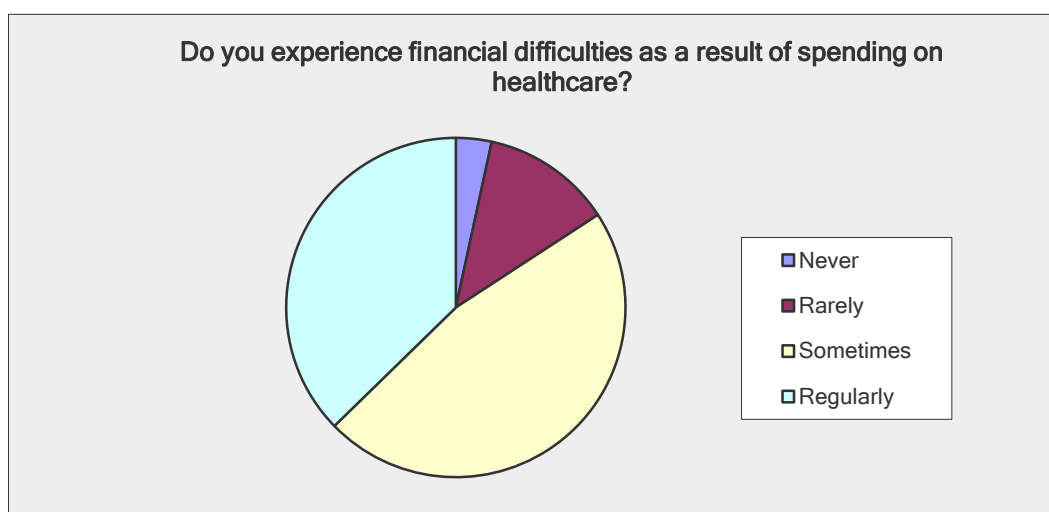


Figure 8. Experience of financial difficulties of respondents who can make ends meet with some difficulty, with difficulty or with great difficulty

When asked about whether they faced financial difficulty as a result of spending on healthcare the two groups also responded very differently (Figures 7 and 8), with the “difficulty” income group declaring facing difficulty at least sometimes or regularly more often than the “easy” income group.

When asked whether they had to reduce spending on essential needs, the “difficulty” income group replied yes at 64% while the “easy” income group replied yes at 19.1%. The “difficulty” income group also postponed or did without receiving treatment or making healthcare visits because of costs significantly more than the “easy” group, and disagreed in a larger proportion that their healthcare costs were covered to a sufficient degree by their healthcare system.

The need to have recourse to a private or complementary health insurance was however fairly similar in the two groups of respondents.

When looking at the **accessibility** component the “difficulty” income group declared facing more delays than the “easy” group for all of the services listed in the question (your medicine(s), a treatment intervention, such as surgery or other procedure, a medical device or medical equipment, a diagnostic test, an appointment with a nurse, an appointment with a primary care doctor, with a specialist, help/support from social services). People within the “easy” group replied yes more often when asked if specialists and general practitioners were located close enough to their home (75% versus 60% for the “difficulty” group for specialists, 93% versus 85.4% for the “difficulty” group for general practitioners). When asked about whether they needed to travel to another city, region or country to seek healthcare, both groups had fairly similar responses, except for travel to another region which was somewhat

more often reported by respondents from the “difficulty” group (with 21% needing to travel to another region to seek healthcare services versus 15.7% for the “easy” group.)

As regards **adequacy**, when asked about communication with healthcare professionals, the “difficulty” group replied that they were only sometimes satisfied as regards adequacy of information provided by healthcare providers, involvement in decision regarding their care, or receiving care adapted to their needs. The “easy” group replied in majority they were “very often” satisfied on all of these statements. Both groups however indicated that their healthcare provider never captures their feedback.

Regarding quality and safety of services, both groups replied more often that they were very often satisfied with the safety of the care provided to them (though a larger proportion of the “easy” group replied they were always satisfied with safety than in the “difficulty” group). Regarding continuity of care and respect of standards, the majority of respondents in the “difficulty” group replied that they “sometimes” receive good quality of care according to standards and are satisfied with quality of care, while the “easy” group chose in majority the option “very often”.

Regarding **appropriateness**, respondents in the “easy” group replied more often that they did not face any sort of stigma while seeking healthcare (they replied no at 57.6% while in the “difficulty” group 35.7 % of respondents replied no). As to the particular form of stigma they faced, more respondents from the “difficulty” group declared there is less healthcare facilities in their community, that they face inappropriate language or refusal to provide them with treatment.

COMPARISON FOR MEMBER STATES WHO JOINED BEFORE AND AFTER 2004

In this part, we compare the data of these two groups of member states:

- Member states who joined the EU before 2004 (thereafter referred to as group 1): Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, the Netherlands, Portugal, Spain Sweden, United Kingdom
- Member states who joined the EU after 2004 (thereafter referred to as group 2): Bulgaria, Croatia, Cyprus, Czech Republic, Hungary, Latvia, Lithuania, Malta, Poland, Romania, Slovakia, Slovenia

There were 255 respondents in the first group, and 136 respondents from the second group of Member States.

When asked about **overall ease of access to healthcare** in the past 12 months, while both groups replied in majority “moderate”, respondents from group 1 replied in a somewhat

larger proportion that it was very easy (11.86 %) or easy (30.04%), while for respondents from group 2 2.2% replied very easy and 25% replied easy.

Regarding **affordability of healthcare**, when asked whether they experienced financial difficulties as a result of healthcare, respondents from group 2 replied in a larger proportion facing such difficulty regularly (26.1% replied so, while 19.1% of respondents in group 1 chose this option) and sometimes (46.3% reported this answer in group 2, 35.2% in group 1). Conversely, respondents from group 1 replied more often that they never experienced such difficulties (22.9% of respondents in group one, whereas only 8.2% in group 2). Group 2 indicated in a somewhat larger proportion that they had to reduce spending on essential needs such a food or clothing to cover healthcare cost in the past 12 months (46.6% indicated so, versus 38.3% in group 1), and also indicated they went without or postponed healthcare visits or treatment in a larger proportion than group 1 (see Table 6 and 7 below).

| In the past 12 months, did you forgo (do without) or postpone healthcare visits because of cost? | | |
|--|------------------|----------------|
| Answer Options | Response Percent | Response Count |
| Never | 48.9% | 66 |
| 1 time | 12.6% | 17 |
| 2 times | 20.0% | 27 |
| 3 or more times | 18.5% | 25 |
| answered question | | 135 |
| skipped question | | 1 |

Table 6. Group 2 answers

| In the past 12 months, did you forgo (do without) or postpone healthcare visits because of cost? | | |
|--|------------------|----------------|
| Answer Options | Response Percent | Response Count |
| Never | 65.1% | 164 |
| 1 time | 11.9% | 30 |
| 2 times | 10.7% | 27 |
| 3 or more times | 12.3% | 31 |
| answered question | | 252 |
| skipped question | | 3 |

Table 7. Group 1 answers

The two groups also had very different answers when asked whether their healthcare systems sufficiently cover their healthcare costs. Group 1 selected more frequently the answer “strongly agree” than group 2 (23% in group 1, 6.1% in group 2), while group 2 selected significantly more often “disagree” and “strongly disagree” (24.4% and 14.8% respectively, versus 13.9% and 9.5% who gave a similar answer from group 1).

In the **accessibility sub-heading** of the survey, when asked about delays in obtaining some services, responses of the two groups varied as follows:

- Respondents from group 1 indicated in a somewhat larger proportion than those of group 2 that they faced delays in seeking a treatment intervention or surgery, diagnostic tests, appointments with nurses and primary care doctors.

- Respondents from group 2 indicated in a somewhat larger proportion than group 1 that they faced delays in accessing medicines, medical equipment, appointments with specialists and support from social services.

When asked whether they need to go to another city, region or country to seek the healthcare they need, a somewhat larger proportion of group 1 respondents (40.6%) needed to go to another city than in group 2 (36.6%), while a larger proportion of group 2 respondents declared they need to go to another country (17.9%) than group 1 (4.8%)

For questions related to **adequacy of healthcare**, when asked about communication with their healthcare professionals group 2 often chose in majority the option “sometimes” whereas group 1 chose more often the response “very often” when asked about whether their healthcare professionals inform them adequately and involve them in the decision making process about their care or adapt their care to their needs. The majority of respondents in both groups replied healthcare professionals “never” capture their feedback.

For questions regarding whether care provided to them is up to quality standards and satisfaction as regards safety and continuity of care, both groups replied either very often or sometimes in majority to all questions but group 1 replied in a larger proportion that they are always satisfied for these 3 items than group 2.

For the part of the questionnaire which looked at **appropriateness** for different groups of patients, differences in responses can also be noticed. When asked whether they ever experienced stigma when seeking/receiving healthcare, group 2 indicated they were somewhat more stigmatised on all groups proposed in the list, except to the response “for being a woman”. Overall, 49 % from group 1 declared they never experienced such stigma, while 41.8% of group 2 declared the same. Regarding types of stigma/discrimination faced, group 1 reported in a more important proportion that the issue was the attitude of healthcare staff (70% in group 1 indicated this, while 57.7% indicated this in group 2).

Conclusions and recommendations

CONCLUSIONS

The survey on access to healthcare is the first study conducted by the European Patients’ Forum to gather knowledge on the experience of patients with chronic and long term conditions on access to healthcare in the European Union, and to identify potential challenges and barriers to access, and possible solutions. The survey confirms the experiential knowledge

and previous evidence gathered by the European Patients' Forum and the patient community illustrating that patients face multiple barriers in accessing healthcare across the European Union. The survey results also show that from the patients' perspective important disparities in access to healthcare exist, which tends to confirm that there are inequalities in access to healthcare in the European Union.

Availability

The data collected in relation to availability shows that the most frequent response for ease of access to healthcare is moderate, and more than a quarter of respondents indicate it is difficult, showing that there are obstacles in accessing healthcare for many patients.

When asked about information on availability of healthcare, respondents confirmed that the internet is increasingly considered as a reliable source of information for many patients. Conversely, results also indicated that health authorities and insurances need to make more effort in communicating quality information to patients. Patients were also not satisfied with the quality of health information provided at work, at school, or on television.

A worrying trend highlighted by the survey is that respondents indicated more frequently that they find information on available healthcare is not easy to find, nor accessible for people with disability, nor transparent on costs, nor easy to understand. The only positive point highlighted by patients is that such information is useful. These findings indicate an important need for improvement in healthcare in relation to information to patients. Information on available healthcare is a stepping stone for patients to find the services they need, and without quality information on healthcare services, healthcare systems are difficult to navigate.

Affordability

The results of the questionnaire show that a large group of patients do face financial hardship because of the cost of healthcare. About 60% of respondents have faced difficulties at least sometimes as a result of spending on healthcare and one fifth of respondents faced such difficulties frequently.

Patients have more difficulties to pay for some services than others, for example specialised doctors or specialised healthcare professionals are less affordable than primary care doctors. For most services aside from primary care doctors, less than half of patients declared they can always afford it.

A large proportion of respondents (41%) reported reducing household spending on essential needs, such as food or clothing to be able to afford healthcare, and a similarly large proportion of respondents indicated they sometimes had to do without or postpone healthcare visits or treatment. This is an alarming finding, given that postponing healthcare can lead to worse health outcome whereas early diagnosis and intervention can be crucial in the management of chronic conditions and to support patients in staying in active employment.¹⁴ While approximately half of the respondents agreed their healthcare system is covering enough of their healthcare costs, the other half disagreed or stayed neutral. This seems to confirm inequalities in patients' access to healthcare in the EU, as also shown by the responses to open ended questions which indicate patients face a variety of barriers and some patients face more unmet needs than others.

Some respondents also indicate that they face a paradoxical situation where healthcare is affordable, but not in a timely way, or the specific service or treatment they would need is not available, showing that while affordability is essential, other components of access also have to be in place as well in order for patients to effectively have access to healthcare.

Accessibility

When asked for barriers other than financial, respondents indicated other challenges linked to accessibility. Most respondents indicated they did not face delays in accessing most services, except for access to specialists. However, approximately one fifth of patients also declared having faced delays for all other services, except for diagnosis where almost two fifths of respondents have faced delays. In many chronic conditions, early intervention can be crucial to stop or slow down progression of the disease so significant delays to access to diagnostic tests can have a negative impact for patients.

Most respondents indicated that location of some core health services (including GPs, pharmacists, hospitals and specialists) was close enough to their home. However, for specialists there is a more notable gap, as approximately one third of participants felt specialists were located too far away. While approximately half of respondents do not need to travel to another city or region to seek healthcare, a large proportion do need to travel to a different city (40%) and a somewhat smaller proportion need to go to another region or country (17.7%). Our survey indicates that approximately 9% of respondents go to another

¹⁴ <http://www.eu-patient.eu/News/News/early-intervention-key-to-quality-of-life-and-sustainable-health-systems/>

country and use cross border healthcare, which is somewhat more important than the WHO estimates (2 to 5 percent of patients seek healthcare abroad)¹⁵. This potentially indicates that patients with chronic diseases or long term conditions may use cross border healthcare somewhat more than the general population.

While the survey overall showed that for the majority of respondents, delays and lack of services nearby is not a significant challenge, the survey did indicate some specific challenges with regards to accessibility to specialists, and delays with diagnostics which need to be addressed. In addition, one fifth of respondents indicated constant delays for access to all services listed in the questionnaire. More research may be needed to understand where delay to service access is a challenge and which categories of patients are affected. However, data comparisons do indicate that respondents from households that face some level of difficulty to make ends meet with their income, as well as respondents from new EU Member States, respondents who have multiple conditions, and respondents living in urban areas may face more delays.

Adequacy

When asked about the quality of the patient-healthcare professional relationship, it is encouraging to see that a majority of respondents indicated that their healthcare professionals inform them adequately about their treatment options and very often involve them in the decision about their care. However, a consistent 15-20% of respondents report negative experiences on all of these accounts, once again highlighting unequal experiences in access to quality of healthcare.

Respondents did indicate some issues in relation to information on the safety of their treatment and in relation to adapting care to their changing needs, and, alarmingly, many respondents pointed out that their feedback on quality is never captured by their healthcare professionals. This indicates gaps in implementing patient centred healthcare and shared decision making, and that patients are very much an untapped resource in relation to improving the quality of care, as their feedback is not collected.

Results in relation to safety and quality of care are also encouraging, as participants indicated more frequently that their care is at least very often up to standard, and that they are satisfied with continuity and safety of their care. However, around 40% of respondents also indicated

¹⁵ http://www.euro.who.int/_data/assets/pdf_file/0011/120332/E88697.pdf, p 18

more negative experiences, such as being only sometimes, rarely or never satisfied of all these issues. This once again leads to the conclusion that patients face very unequal experiences as to quality and safety of care.

Appropriateness

When asked about appropriateness of healthcare, which means whether it is responsive to the need of different groups, respondents highlighted very important gaps. Most respondents reported that they had experienced some form of stigma while seeking or receiving healthcare. While various grounds for stigma were proposed, it is interesting to note that more than one third of patients indicated experiencing stigma because of their chronic condition(s). This confirms that health status or having a chronic condition can alone be a cause for stigmatisation, though it is for example not one of the grounds recognised in the EU treaty when it comes to tackling discrimination.¹⁶ The main issue highlighted by respondents is the attitude of the healthcare staff, showing the need for more training in communication and human rights related aspects for healthcare professionals and staff of healthcare institutions. Other issues pointed out by one fifth of respondents highlight inappropriate language, denial of rights or appropriate treatment, and lack of healthcare facilities.

Unmet needs and unequal experiences as to access to healthcare in the European Union

Responses to open-ended questions towards the end of the questionnaire complement the information gathered throughout the survey and tell a story of unmet needs and unequal experiences in healthcare across of the European Union. They give further insight on some of the barriers patients in the European Union face in accessing healthcare: waiting times, unaffordable services (e.g. dental care), lack of patient centeredness and coordination, underfunded healthcare services or inadequate use of the healthcare budget, unaffordable medicines and corruption. Respondents identified key problems to address and suggested political actions to improve access to healthcare in their Member States. This shows that patients and their informal carers have a key role to play in order to solve access issues.

What we learnt on specific groups of respondents

Given the low proportion of respondents from **rural areas** compared to those from urban areas, there is a need for further research on the impact of living in rural versus urban areas on patients' access to healthcare. The comparison of data does suggest some disparities in some dimensions of access to healthcare, with patients in urban areas declaring somewhat

¹⁶ <http://fra.europa.eu/en/charterpedia/article/21-non-discrimination>

more difficulties in affording healthcare, and somewhat more delays in accessing various services, while patients in rural areas face more geographical barriers and need to travel further to seek the healthcare they need.

Results of patients with a single disease versus patients with several diseases indicates that **patients with several chronic conditions** may have somewhat more difficulties in affording healthcare, face more delays and need to travel more to get the services they need.

The comparison of data according to income suggests that for **participants who declared making ends meet with some difficulty, difficulty and great difficulty**, income has a negative impact on their experience in accessing healthcare. The largest impact can be noted as regards affordability of healthcare, but it also seems to impact to some extent all other areas of access.

Results also suggest that there are disparities in experiences for **respondents from Member states who accessed the EU before and after 2004**. The latter group indicated more affordability issues, were also somewhat less satisfied with adequacy of healthcare, and indicated facing somewhat more stigma and discrimination. Both groups indicated facing delays in accessing healthcare in different categories, and more respondents from Member States who joined after 2004 indicated the need to go to another country to seek the healthcare services they need. However, more research is needed to understand disparities across the different macro-regions of the EU as regards access to healthcare, clustering similar welfare systems.

Are we on the right track to achieve universal health coverage across the European Union?

Overall the results of EPF's survey on access to healthcare indicates that patients with chronic and long term conditions from all EU Member States face a variety of barriers in accessing healthcare, with a clear picture of inequalities according to income and according to which part of the EU they live in. Patients from "new" Member States that have joined the EU after 2004 (central and eastern European Member States, Malta and Cyprus) indicated more unmet needs than these living in Member States that had joined the EU before 2004. The survey also confirms that access to healthcare is a complex, multi-dimensional issue. Common challenges across the EU exist and more distinct additional barriers are present in some regions of the EU or specific Member States. Therefore, to tackle access barriers, a comprehensive strategy is needed encompassing both EU and national levels.

EU countries have committed to the global targets of the United Nations sustainable development goals (SDGs), and in particular the SDG on health and target of achieving universal health coverage for all by 2030. In this regard, our survey indicates that there are

still many challenges to overcome before attaining universal health coverage for all in the EU. This is the reason for which decisive political actions are needed in order to get back on track for this target. As some participants to the survey have highlighted, the current picture in healthcare is one of cuts in spending on healthcare and increasing co-payments in various EU countries, indicating that the EU is for the moment not on the right track towards achieving the UN target, and needs a different political strategy in order to achieve its commitments on access to healthcare.

RECOMMENDATIONS

The survey's results point to fundamental challenges to tackle and key areas of action for decision makers. The survey shows that many barriers encountered by patients in accessing healthcare are common across the European Union, though there are also significant differences, for example between pre-2004 and post-2004 EU accession Member States. Policy actions are needed both at European and national level to improve access to healthcare for patients with chronic conditions. While the organisation of healthcare is a national competence, the EU has a key supporting role to play in order to improve access to healthcare for patients and to ensure the right to health stated in the EU charter of fundamental rights is implemented.

Many of the recommendations made below stem from responses to open ended questions. Following the results of the survey, EPF recommends that decision makers at national and EU level put in place a comprehensive access to healthcare strategy comprising the following recommendations:

- To improve access to quality healthcare information to patients **more transparency towards patients with chronic and long term conditions, their informal carers and the public** is needed, including more transparent information on what the healthcare system provides and on the costs and quality of care.
- To comprehensively address the **unaffordability of healthcare** which many patients have highlighted in the survey and for which various causes are mentioned. Specific political measures are needed to address the following issues:
 - **Lower income groups** indicate facing more financial hardship because of healthcare than higher income groups, indicating that more tailored support measures would be needed in order to ensure affordable healthcare. Measures to ensure groups of patients that are the most vulnerable to financial hardship as a result of healthcare costs (patients with low income, with multimorbidity) are appropriately supported and have appropriate coverage of their healthcare both in terms of limiting co-payments and

ensuring all products and services they need are encompassed in their coverage.

- There is a **lack of coverage** of certain services or products in healthcare that are a necessity for patients as a result of their condition (physiotherapy, psychotherapy, dental care etc....). These needs should be considered.
- Some patients indicate their care is not covered because their disease is not **recognised**. It is important to ensure Member States' measures to ensure coverage for the care of chronic and long term conditions do not exclude specific diseases or rare diseases, and work together with patients' organisations in order to identify these unmet needs.
- More **transparency** on the basket of care covered by the healthcare system and by insurances is needed.
- **Assessment and decisions** with respect to what services are covered as part of the basket of care should be taken with the meaningful involvement of patient organisations, in order to ensure that important services are not left out, and that all chronic conditions are appropriately recognised by the healthcare system.
- To ensure **sustainable investment in healthcare services in all Member States**, discontinuing undue cuts in the healthcare budget and ensuring resources are employed adequately is essential. Many patients highlighted in particular the need for more resources to be allocated to the health workforce, in order to reduce waiting times in some EU countries where it is highlighted as a major issue for patients and to ensure that healthcare professionals have the appropriate amount of time to communicate with patients.
- To collect **existing good practices** on the communication between patients and healthcare professionals, on the use of standards of care, and on ensuring continuity and adaptation of care to patients' changing needs, in order to promote them and scale them up across the European Union.
- To encourage healthcare providers to **seek the feedback** of patients and informal carers on quality and safety of care in a more systematic way, in order to ensure that patients' insight on gaps and opportunities for improvement of healthcare services is used.
- To ensure that healthcare professionals receive **appropriate training on human rights** as well as communication and listening to improve the patient-healthcare professional relationship.
- To promote **good practices regarding the training of healthcare professionals** as regards caring for various vulnerable groups including for example young patients and

LGBTI people, with appropriate and knowledgeable stakeholders, whether they come from NGOs representing such groups, universities or other educational institutions.

- To ensure that healthcare professionals and in particular medical professions have more **in depth training about chronic conditions** and have adequate access to resources and expertise on rare conditions and on existing standards of care for various chronic conditions.
- To identify, with the involvement of patients and consumers, Member States where **corruption** is a problem and put in place appropriate policy responses defined with stakeholders (including patients), to tackle such corruption as it obstructs patients' access to high quality, equitable healthcare. Such responses should include appropriate sanctions. The EU also has a key role to play in monitoring corruption in healthcare, through appropriate indicators defined with stakeholders including patients' organisations.
- To address the barriers that impede on **patients' access to medicines** such as the long period before access to innovation is possible, issues of shortages and unavailability of a treatment with proven added therapeutic value, and high prices of some medicines.
- **Organisational changes** are needed to ensure an improved access to specialist healthcare professionals, to improve patient centeredness of care, to ensure the package of services covered by the healthcare system is tailored to the need of patients with chronic and long term conditions and to promote better coordination of care.
- **To involve patients and their organisations in decision making about healthcare** and in monitoring quality of care. As demonstrated by respondents of the survey, the experience of patients and informal carers is essential to accurately identify barriers to healthcare access and the policy responses needed to tackle them.

Annex I– Survey template

Introduction

This is a unique EU-wide survey which was designed by patients and patients' representatives. It is aimed at capturing the experience of patients across diseases and member states as regards various dimensions of access to healthcare and treatment.

What is the survey about?

This survey aims to gain knowledge on the perception of patients across the European Union as to access to healthcare. It looks at 5 dimensions of access to healthcare:

- Availability – whether a healthcare service or product is available in the healthcare system of your country
- Affordability – whether seeking healthcare causes financial hardship to patients.
- Accessibility– Whether there are barriers, other than financial (e.g. waiting lists, geographical barriers...), that stop patients from accessing healthcare
- Adequacy – the quality of healthcare and involvement of patients in shared decision making with their healthcare professionals
- Appropriateness – whether healthcare meets the need of different groups in the population

Who is the survey for?

This survey is aimed at individual patients with chronic or long-term conditions and their family members or informal carers.

You do not need in-depth knowledge on healthcare to complete this survey, questions are primarily about your experience, there is no wrong or right answers.

How much time will it take?

This survey consists of 30 questions, some of which have tick-box options. It should take around 20-25 minutes to complete. Please note that you do need to answer all the questions, unless the question is marked as “optional”.

The survey is open until 31 October 2016.

Will my identity be published?

The survey is anonymous. We only ask for information necessary to analysing the results, e.g., demographic and country information. No personal information will be published. If you wish to be contacted further, for example for an interview, you can provide your contact details. By completing and submitting this survey, as a participant, you are providing your informed consent.

How will the survey responses be used?

The survey is run by the European Patients’ Forum, a non-governmental organisation that works with patients’ groups in public health and health advocacy across Europe. Our members represent specific chronic disease groups at EU level or are national coalitions of patients. This survey is crucial for the European Patients’ Forum, as its results will be used to inform our advocacy work on access to healthcare and health inequalities at EU level, including an EU wide campaign on access to healthcare in 2017.

The survey report will be published and available for free on EPF website.

If you need additional information about the questionnaire or clarifications on the content, please do not hesitate to write at the following email address: laurene.souchet@eu-patient.eu

Thank you for your support!

The EPF team

2016 EPF Access Survey

DEMOGRAPHIC AND HEALTH QUESTIONS

* 1. Are you:

- A patient with a chronic or long term condition
- A patient with several chronic and long term conditions
- A family/informal carer
- A patient and informal carer
- None of the above

2. Are you filling this questionnaire:

- On your behalf
- On somebody else's behalf

3. What age are you (or the patient you are responding on behalf of):

4. What is your gender:

- Male
- Female
- Intersex
- Transgender
- Prefer not to say

5. Your country of residence is:

Austria

Belgium

Bulgaria

Croatia

Cyprus
Czech Republic
Denmark
Estonia
Finland
France
Germany
Greece
Hungary
Ireland
Italy
Latvia
Lithuania
Luxembourg
Malta
Netherlands
Poland
Portugal
Romania
Slovakia
Slovenia
Spain
Sweden
UK

6. Do you live in:

- An urban area (a city or city suburb, a medium to large town)
- A rural area (open countryside, a village/small town)

7. A household may have different sources of income and more than one household member may contribute to it. Thinking of your household's total monthly income: is your household able to make ends meet?

- Very easily
- Easily
- Fairly easily
- With some difficulty

- With difficulty
- With great difficulty
- Don't know
- Prefer not to say

AVAILABILITY OF HEALTHCARE

8. Thinking of access overall, how difficult or easy was it to actually obtain the healthcare services you needed within the past 12 months?

- Very difficult
- Difficult
- Moderate
- Easy
- Very easy

9. How would you rate access to information on available healthcare services from the following sources or channels?

(Answer choices: Very poor, Poor, Average, Good, Very good, Not applicable to me)

- School
- Work
- The doctor's practice
- Hospitals
- Pharmacies
- Internet websites
- Social media
- TV
- Patient organisations
- Relatives and peer patients
- Public health authorities
- Insurance companies

10. Would you agree with the statement: information about available healthcare services is:

(Answer options: Yes, No, Unsure)

- Easy to find
- Easily accessible for
- people with disabilities
- Easy to understand

- Useful
- Transparent on the financial (out-of-pocket) costs

AFFORDABILITY OF HEALTHCARE

11. When you need it, can you afford (financially) to access:

(Answer options: Always, Very Often, Sometimes, Rarely, Never, Not applicable)

- Primary care doctor
- Specialist doctor
- Specialised healthcare providers (e.g. physiotherapist, psychologist, etc.)
- Hospital
- Medicine
- Medical equipment or device (including the necessary consumables, e.g. diagnostic test, wheelchair, etc.)
- Dental health care
- Cosmetic intervention/reconstruction necessary as a result of your condition

12. Do you experience financial difficulties as a result of spending on healthcare?

- Never
- Rarely
- Sometimes
- Regularly

13. In the past 12 months, did you reduce your spending on essential needs, such as food or clothing, to be able to cover healthcare costs?

- Yes
- No

14. In the past 12 months, did you forgo (do without) or postpone healthcare visits because of cost?

- Never
- 1 time
- 2 times
- 3 or more times

15. In the past 12 months, did you forgo (do without) or postpone treatment because of cost?

- Never
- 1 time
- 2 times
- 3 or more times

16. What do you think of the statement: My healthcare costs are covered to a sufficient degree by my healthcare system (whether it is tax based or social insurance based):

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree
- Don't know

17. Do you need to have recourse to a private or complementary health insurance in order to cover your healthcare cost?

- Yes
- No
- Don't know

18. Do you have any other comment on your healthcare coverage?

ACCESSIBILITY OF HEALTHCARE

19. Over the past 12 months, have you experienced a significant delay in accessing:

(Answer options: Yes, No, Not applicable to me)

- Your medicine(s)
- A treatment intervention, such as surgery or other procedure.
- A medical device or medical equipment
- A diagnostic test
- An appointment with a nurse
- An appointment with a primary care doctor (e.g. a general practitioner)
- An appointment with a specialist
- Help/support from social services

20. Would you say the following services are located near enough from your home?

(Answer options: Yes, No)

- A pharmacy
- A GP
- A specialist
- A hospital

21. Do you face any of the following issues when seeking care for your condition(s)? Mark all that apply.

- I need to go to another city to get the service I need
- I need to go to another region to get the service I need
- I need to go to another country to get the service I need
- None of the above

22. To overcome this geographical barrier, do you have access to:

- A mobile or eHealth service to help you access healthcare remotely
- Financial support for travel
- Transportation
- None of the above
- Other (please specify)

ADEQUACY OF HEALTHCARE

23. Please rate the statements below that relate to the communication with your healthcare providers.

(Answer options: Always, Very Often, Sometimes, Rarely, Never)

- I'm adequately informed by healthcare providers about my treatment options
- I'm involved in decisions regarding my care by my healthcare providers
- My healthcare providers give me the information I need about the safety of my treatment
- My healthcare provider adapts my care according to my changing needs
- My healthcare providers are capturing my feedback on quality of care provided

(through satisfaction survey or other means)

24. Would you agree with the following statement on the quality and safety of your care?

(Answer options: Always, Very, Often, Sometimes, Rarely, Never, I don't know)

- I receive good quality care according to the standard/ guidelines or best practices available

- for my condition
- I'm satisfied with the safety of care provided to me
- I'm satisfied with continuity in my care over time

APPROPRIATE HEALTHCARE

25. Have you ever felt stigmatised when seeking or receiving healthcare because of (mark all that apply):

- Your young age
- Your older age
- Your physical disabilities
- Your intellectual disabilities
- Your mental health status
- Your chronic/long term condition
- Your ethnicity
- Being a woman
- Being a man
- Being intersex
- Being transgender
- Your income/social status
- Your religion
- Your sexual orientation
- No
- Other (please specify)

26. What type of stigma or discrimination did you experience? Mark all that apply.

- Attitude of healthcare staff
- Denial of my rights
- Inappropriate language
- Lack of healthcare facility in my community
- Refusal to provide me with treatment
- Other (please specify)

27. What measures need to be taken to prevent this situation?

Conclusions

28. What do you think is the most important action policy makers could take to improve access to healthcare in your country?

29. Do you have any other comments regarding any aspects of access to healthcare in your country?

30. EPF may need to contact some participants for follow up interviews. If you would consent to be contacted for a follow up interview, please provide your e-mail address.

The survey is now completed. We thank you for your participation!



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The content of this survey report represents the views of the author only and is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.