

### Survey Introduction and Information

**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](mailto:laurene.souchet@eu-patient.eu)**

**Thank you for your support!**

**The EPF team**

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:

- A 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?

	Very poor	Poor	Average	Good	Very good	Not applicable to me
School	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The doctor's practice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hospitals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pharmacies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Internet websites	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social media	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient organisations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relatives and peer patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Public health authorities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insurance companies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

	Yes	No	Unsure
Easy to find	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Easily accessible for people with disabilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Easy to understand	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Useful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transparent on the financial (out-of-pocket) costs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

AFFORDABILITY OF HEALTHCARE

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

	Always	Very Often	Sometimes	Rarely	Never	Not applicable
Primary care doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialist doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialised healthcare providers (e.g. physiotherapist, psychologist, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hospital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical equipment or device (including the necessary consumables) (e.g. diagnostic test, wheelchair, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dental health care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cosmetic intervention/reconstruction necessary as a result of your condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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 an significant delay in accessing:

	Yes	No	Not applicable to me
Your medicine(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A treatment intervention, such as surgery or other procedure.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A medical device or medical equipment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A diagnostic test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An appointment with a nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An appointment with a primary care doctor (e.g. a general practitioner)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An appointment with a specialist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help/support from social services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

	Yes	No
A pharmacy	<input type="radio"/>	<input type="radio"/>
A GP	<input type="radio"/>	<input type="radio"/>
A specialist	<input type="radio"/>	<input type="radio"/>
An hospital	<input type="radio"/>	<input type="radio"/>

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.

	Always	Very Often	Sometimes	Rarely	Never
I'm adequately informed by healthcare providers about my treatment options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm involved in decisions regarding my care by my healthcare providers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My healthcare providers give me the information I need about the safety of my treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My healthcare provider adapt my care according to my changing needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My healthcare providers are capturing my feedback on quality of care provided (through satisfaction survey or other means)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

	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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm satisfied with the safety of care provided to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm satisfied with continuity in my care over time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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!