

Introduction

What is the survey about?

The aim of this survey is to gather more information on the lived experience and impact of the COVID 19 pandemic on patients with chronic conditions, their communities and on patients' organisations.

The scope of this survey will cover the impact of COVID 19 responses on diagnosis, treatment and care access and provision as well as social dimensions. The survey will also assess how the pandemic is affecting the work and livelihood of patients' organisations.

Who is the survey for?

The survey includes two separate sets of questions. The survey includes one questionnaire for individual patients with chronic or long-term conditions, their family members or informal carers and patients' communities, and another for patients' organisations. 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 **10-15** questions, some of which have tick-box options, depending on whether you are answering as a Patient organisation or as individual patient and communities. It should take around **15-20** minutes to complete. Please note that you do need to answer all the questions. In our analysis we can only take into consideration completed surveys in order to have reliable and comparable results.

What is the deadline for completing the survey?

The survey is open until **11 October 2020**.

Will my identity be published?

The survey is anonymous and the results will be treated as strictly confidential. We only ask for information necessary to analysing the results, e.g., demographic and country information. No personal information will be published. By completing and submitting this survey, as a participant, you are providing your informed consent.

How will the survey responses be used?

With the results of this survey, EPF intends to produce a comprehensive report that will serve as a strong evidence base for our policy and advocacy work and make recommendations towards EU institutions' policymakers, which we hope will ultimately inform the decisions that are taken at EU and national level.

Immediately, the results will be used to inform EPF's key asks in view of the EU4Health programme negotiations. This survey is part of EPF's continued efforts to gather COVID 19-related experiences and insights from the patient community.

The survey report will be published and available for free on EPF website in the coming months. If you need additional information about the questionnaire or clarifications on the content, please do not hesitate to write to: policy@eupatient.eu

Thank you for your support! The EPF Secretariat

General information about you

* 1. I am responding on behalf of a:

- Patient organisation
- Individual patient/carer

General information about you - Patient Organisations - Geographic remit

* 1. What is the geographical remit of your organisation?

- European
- National
- Regional
- Local
- Open question: if regional or local, please state location.

General information about you - Patient Organisations - EU

* 1. Your organisation is based in:

* 2. What disease area(s) does your organisation cover?

- cardiovascular
- neurological
- respiratory
- metabolic
- cancers
- neuromuscular
- rare
- autoimmune
- all of the above
- Other (please specify)

* 3. Which of the below changes has your organisation faced due to the pandemic?

- Change in organisation's focus
- Concerns over organisation's financial stability
- 2020 Work plan revision to ensure our organisation's survival through the pandemic
- Renegotiate milestones for projects that our organisation is undertaking with donor partners
- Measures to assess the impact of the Covid-19 pandemic on our organisation

Please comment should you wish while including reasons for such changes or insert NA if you do not wish to add anything.

* 4. To what extent do you think your organisation's future funding (2021 onwards) will be affected by COVID-19?

- Decrease in public funding
- Decrease in private funding
- Decrease in human resources
- Increase in public funding
- Increase in private funding
- Increase in human resources

Please comment should you wish while including reasons for such changes

* 5. What have proven to be your organisation's most popular (either existing or new) services during the COVID-19 pandemic? Eg. providing online content (such as webinars, videos on legal advice and/or mental health, articles, etc) or possible extra services offered (eg psychological, legal, medical advice, etc). (please insert NA if you do not wish to add anything)

* 6. At this point in time, what are the main COVID-19-related concerns of the patients you represent? (indicate all that apply)

- Personal safety from COVID19
- Lack of clear information and communication from healthcare providers on the availability and accessibility of healthcare services and treatments
- Lack of clear information and communication from national authorities on the availability and accessibility of healthcare services and treatments
- Unclear public health guidance/advice from healthcare providers
- Unclear public health guidance/advice from national authorities
- Shortages of medicines and technologies (not to be confused with treatment delay)
- Paused or delayed diagnosis
- Treatment delay
- Treatment discontinuation
- Access to medication
- Access to healthcare professionals and regular consultations
- Termination of work contract
- Temporary unemployment
- Return to employment
- Continued education
- Risk of poverty
- Isolation
- Social exclusion
- Mental wellbeing
- Feeling forgotten

Please comment if you wish or insert NA if you do not wish to add anything.

* 7. Have any of your members experienced chronic illness and neurological/miscellaneous symptoms, months after having been infected with (confirmed or suspected) COVID-19?

- No
- Yes

If yes, please describe the situation and frequency of these experiences or insert NA if you do not wish to add anything.

* 8. How appropriate were the protection measures put in place by EU governments to the vulnerabilities and protection of people with chronic conditions in particular?

- Appropriate – e.g. measures put in place were particularly appreciated by the patients my organisation represents
- Partially appropriate – e.g. Some of the measures put in place had a mild or partially positive impact on the patients my organisation represents
- Not appropriate – e.g. measures put in place had a negative impact on the patients my organisation represents

Please comment further if you wish by providing examples (please insert NA if you do not wish to add anything)

* 9. In your experience, to what extent were patients and their representatives involved in the management of this pandemic?

- Good patient involvement – e.g. patients were represented within their country's crisis task force e.g. 2 patients and their organisations were involved in the reorganisation of healthcare during lockdown
- Very little meaningful patient involvement – e.g. my organisation was contacted by the authorities/ hospitals to share information about the measures put in place with our members
- No patient involvement – e.g. patients were not consulted at any stage of the management of the pandemic and people with chronic conditions were completely forgotten in the government's response to the pandemic
- Other (please specify)

* 10. At this point in time, what are the three most important things that your national government(s) and health care system(s) should be focusing their efforts on? (you can select up to 3 answers)

- Accessible, affordable and equitable telemedicine solutions
- Investing in and improving healthcare capacity
- Alternative solutions to accessing treatment/medicines, e.g. home delivery or pharmacy pickup
- Better data collection (e.g. to swiftly identify local outbreaks; in research for treatments and vaccines)
- Easily accessible COVID-19 testing framework and facilities
- Increased information on COVID-19 prevention
- Secure access to effective and safe COVID-19 vaccine
- Secure access to effective and safe COVID-19 treatments
- Other - Please feel free to add details or examples of the telemedicine solutions you have used during this period or have experience of (please insert NA if you do not wish to add anything).

* 11. What are your organisations' most important recommendation(s) to the EU on improving the management of the COVID-19 crisis and ensuring the protection of patients with chronic conditions? (please insert NA if you do not wish to add anything)

12. If you agree to either be contacted further, for example for an interview, or if you agree to be quoted, please provide contact details (name of your organisation and email address) below

Name of your organisation

Email address

Patient Organisations - National/Regional/Local

* 1. Your organisation is based in:

* 2. What disease area(s) does your organisation cover?

- cardiovascular
- neurological
- respiratory
- metabolic
- cancers
- neuromuscular
- rare
- autoimmune
- all of the above
- Other (please specify)

* 3. Which of the below changes has your organisation faced due to the pandemic?

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- Measures to assess the impact of the Covid-19 pandemic on our organisation

Please comment should you wish while including reasons for such changes or insert NA if you do not wish to add anything.

* 4. To what extent do you think your organisation's future funding (2021 onwards) will be affected by COVID19?

- Decrease in public funding
- Decrease in private funding
- Decrease in human resources
- Increase in public funding
- Increase in private funding
- Increase in human resources

Please comment should you wish while including reasons for such changes or insert NA if you do not wish to add anything.

* 5. What have proven to be your organisation's most popular (either existing or new) services during the COVID-19 pandemic? Eg. providing online content (such as webinars, videos on legal advice and/or mental health, articles, etc) or possible extra services offered (eg psychological, legal, medical advice, etc). (please insert NA if you do not wish to add anything)

* 6. At this point in time, what are the main COVID-19-related concerns of the patients you represent? (indicate all that apply)

- Personal safety from COVID19
- Lack of clear information and communication from healthcare providers on the availability and accessibility of healthcare services and treatments
- Lack of clear information and communication from national authorities on the availability and accessibility of healthcare services and treatments
- Unclear public health guidance/advice from healthcare providers
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- Paused or delayed diagnosis
- Treatment delay
- Treatment discontinuation
- Access to medication
- Access to healthcare professionals and regular consultations
- Termination of work contract
- Temporary unemployment
- Return to employment
- Continued education
- Risk of poverty
- Isolation
- Social exclusion
- Mental wellbeing
- Feeling forgotten

Please comment if you wish or insert NA if you do not wish to add anything.

* 7. Have any of your members experienced chronic illness and neurological/miscellaneous symptoms, months after having been infected with (confirmed or suspected) COVID19?

- No
- Yes

If yes, please describe the situation and frequency of these experiences (please insert NA if you do not wish to add anything).

* 8. How appropriate were the protection measures put in place by your government to the vulnerabilities and protection of people with chronic conditions in particular?

- Appropriate – e.g. measures put in place were particularly appreciated by the patients my organisation represents
- Partially appropriate – e.g. Some of the measures put in place had a mild or partially positive impact on the patients my organisation represents
- Not appropriate – e.g. measures put in place had a negative impact on the patients my organisation represents

Please comment further if you wish by providing examples or insert NA if you do not wish to add anything.

* 9. In your experience, to what extent were patients and their representatives involved in the management of this pandemic?

- Good patient involvement – e.g. patients were represented within their country's crisis task force e.g. 2 patients and their organisations were involved in the reorganisation of healthcare during lockdown
- Very little meaningful patient involvement – e.g. my organisation was contacted by the authorities/ hospitals to share information about the measures put in place with our members
- No patient involvement – e.g. patients were not consulted at any stage of the management of the pandemic and people with chronic conditions were completely forgotten in the government's response to the pandemic

Please comment or insert NA if you do not wish to add anything.

* 10. At this point in time, what are the three most important things that your national government(s) and health care system(s) should be focusing their efforts on? (you can select up to 3 answers)

- Accessible, affordable and equitable telemedicine solutions
- Investing in and improving healthcare capacity
- Alternative solutions to accessing treatment/medicines, e.g. home delivery or pharmacy pickup
- Better data collection (e.g. to swiftly identify local outbreaks; in research for treatments and vaccines)
- Easily accessible COVID-19 testing framework and facilities
- Increased information on COVID-19 prevention
- Secure access to effective and safe COVID-19 vaccine
- Secure access to effective and safe COVID-19 treatments
- Other (please explain)

* 11. What are your organisations' most important recommendation(s) to your country's government on improving the management of the COVID-19 crisis and ensuring the protection of patients with chronic conditions? (please insert NA if you do not wish to add anything)

* 12. What are your organisations' most important recommendation(s) to the EU on improving the management of the COVID-19 crisis and ensuring the protection of patients with chronic conditions? (please insert NA if you do not wish to add anything)

13. If you agree to either be contacted further, for example for an interview, or if you agree to be quoted, please provide contact details (name of your organisation and email address) below

Name of your organisation

Email address

Questionnaire for individual patients and communities

* 1. Are you:

- A patient with chronic or long term condition(s)
- A family/informal carer
- A patient and informal carer

* 2. Your country of residence is:

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

- 0-15
- 16-30
- 31-45
- 46-60
- 61-75
- 76 and above

* 4. What is your gender?

- Male
- Female
- Other
- Prefer not to say

* 5. What disease area(s) does your condition(s) fall under?

- cardiovascular
- neurological
- respiratory
- metabolic
- cancers
- neuromuscular
- rare
- autoimmune
- Other (please specify)

* 6. What challenges, if any, have you faced due to the pandemic? (indicate all that apply)

- Lack of clear information and communication from healthcare providers on the availability and accessibility of healthcare services and treatments
- Lack of clear information and communication from national authorities on the availability and accessibility of healthcare services and treatments
- Unclear public health guidance/advice from healthcare providers
- Unclear public health guidance/advice from national authorities
- Treatment delay
- Treatment discontinuation
- Inability to speak to or consult your healthcare professional(s)
- Increased stress and anxiety
- Social isolation
- Employment discontinuation
- Temporary halt of employment
- Risk of poverty
- No particular challenges
- Other (please specify)

* 7. At this point in time, what are your main COVID19 related concerns? (indicate all that apply)

- Personal safety from COVID19
- Continued and timely access to healthcare professionals and regular consultations
- Shortages of medicines and technologies
- Continued employment
- Continued education
- Risk of poverty
- Social exclusion
- Mental wellbeing
- How continued protection of patients during deconfinement and relaxation of restrictive measures is managed in society
- Feeling forgotten
- Other (please specify)

* 8. Thinking of access overall, how difficult or easy has it been to actually obtain the healthcare and services you needed since the beginning of the pandemic?

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

Please comment stating the reasons of your answer or insert NA if you do not wish to add anything.

* 9. Since the beginning of the pandemic, have you experienced a significant delay or obstacle in accessing any of the following (indicate all that apply):

- 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
- Reduced sense of safety when visiting healthcare facilities (or HCPs). E.g. due to COVID19 infection risk
- None of the above
- Please comment

* 10. Based on your experience, what is your preferred telemedicine solution(s)? Please indicate your three preferred solutions.

- Real-time telephone consultation
- Real-time Video consultation
- Exchange with healthcare professional via email
- Remote patient monitoring solutions (e.g. use technological devices to monitor health and clinical signs of a patient remotely)
- Store-and-forward services (Transmission of recorded health history (for example, pre-recorded videos and digital images such as x-rays or photos) through electronic communications means to a practitioner, who uses the information to evaluate the case or render a service outside of a real-time or live interaction)
- Telepharmacy (remote pharmaceutical advice)
- Use of telemedicine mobile health platforms/mobile applications
- Use of interactive electronic health records
- Other (please specify in the textbox below)

Please feel free to add details or examples of the telemedicine solutions you have used during this period or have experience of (please insert NA if you do not wish to add anything).

* 11. How would you rate the following at this stage of the pandemic?

	Very good and clear	Good and generally clear	Average	Poor quality and clarity	Very poor
Clarity of information and communication from healthcare providers on the availability and accessibility of healthcare services and treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clarity of information and communication from national authorities on the availability and accessibility of healthcare services and treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clarity of public health guidance/advice from healthcare providers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clarity of public health guidance/advice from national authorities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 12. Please feel free to comment your responses and provide examples here (please insert NA if you do not wish to add anything).

* 13. If there is anything else that you wish to share relating to the impact that this pandemic has had on your physical and mental health and that we have not directly inquired about, please feel free to include this here (please insert NA if you do not wish to add anything).

14. If you agree to either be contacted further, for example for an interview, or if you agree to be quoted on a first name and country basis (e.g. "Michael with multiple sclerosis from Denmark") please provide your contact details (full name and email address) below

Full name

Email address

Thank you for completing our survey!

If you have not already done so, please share this survey with your network by using this link:

<https://www.surveymonkey.com/r/EPFCovid19>

The deadline to complete the survey is 11 October.

The survey report will be published and available for free on EPF website in the coming months.

For any questions or queries, please contact: **policy@eupatient.eu**