

## Survey Report

# The Impact of the COVID-19 Pandemic on Patients and Patient Organisations

May 2021



## Contents

Introduction .....	3
Individual patient survey.....	4
1.1 Survey results.....	4
1.1.1 Challenges faced by patients .....	5
1.1.2 Access to healthcare .....	6
1.1.3 Patients’ concerns.....	6
1.1.4 Information to patients.....	7
1.2 Discussion.....	8
2. Patients’ organisations survey .....	9
2.1 Survey results.....	9
2.1.1 Functioning of patients’ organisations .....	10
2.1.2 Protection measures .....	12
2.1.3 Involvement of Patients’ Organisations in the management of the pandemic.....	13
2.2 Discussion.....	14
3. Recommendations .....	14
3.1.1 Support for Patients living with Chronic Diseases .....	14
3.1.2 Support for Patient Organisations .....	15
3.1.3 Limitations.....	15
4. Concluding remarks .....	15

## Introduction

This is a report of a survey by the European Patients’ Forum on the impact of the COVID-19 pandemic on patients, carers, and patients’ organisations. The aim of this survey was 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 covers the impact of COVID-19 responses on diagnosis, treatment and care access and provision as well as social dimensions. The survey also assessed how the pandemic has affected the work and livelihood of patients’ organisations.

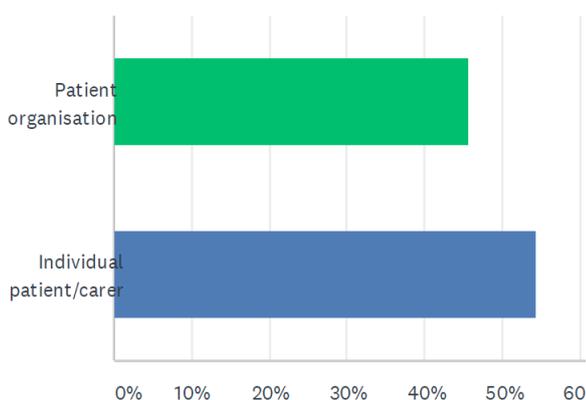
The survey ran for 1 month from 18 September to 18 October 2020. The questionnaire was developed by the EPF secretariat while considering insights from the EPF working group on Universal Access to Healthcare. The survey was disseminated to the entire EPF membership and youth network by email, distributed through the weekly members’ newsletter and on social media.

The results of this survey provide EPF with evidence for our policy and advocacy work. The results will support us in providing the patient perspective to several European initiatives relating to COVID-19, the strengthening of health systems and the digital transformation of healthcare. We hope that recommendations arising from this survey will ultimately inform European and national health policy.

This survey is part of EPF’s continued efforts to gather COVID 19-related experiences and insights from the patient community. EPF will run a second edition of the survey in 2021 with slightly modified questions, based on the responses received, the evolving pandemic situation and emerging knowledge about its impact.

This survey received a total of 125 responses. It included 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. To have reliable and comparable results, all questions were mandatory.

*Respondent categories*



**A good balance of patient organisations and individual patients or carers responded to our survey.** Out of all respondents, 46% were patient organisations and 54% were individual patients or carers.

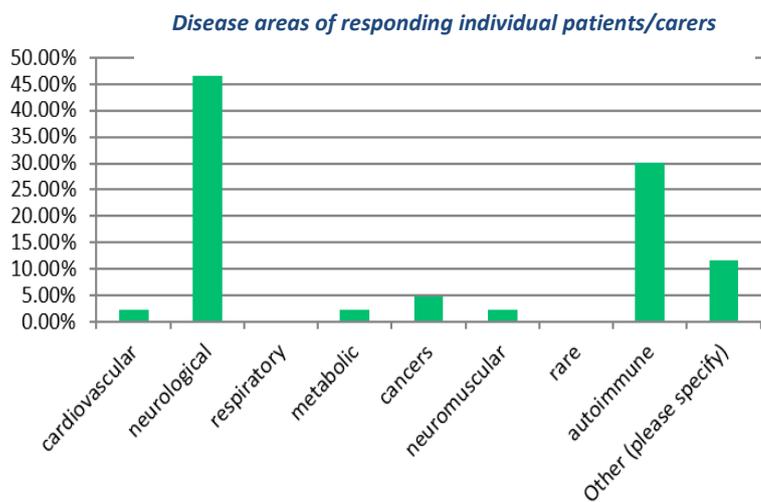
# Individual patient survey

## 1.1 SURVEY RESULTS

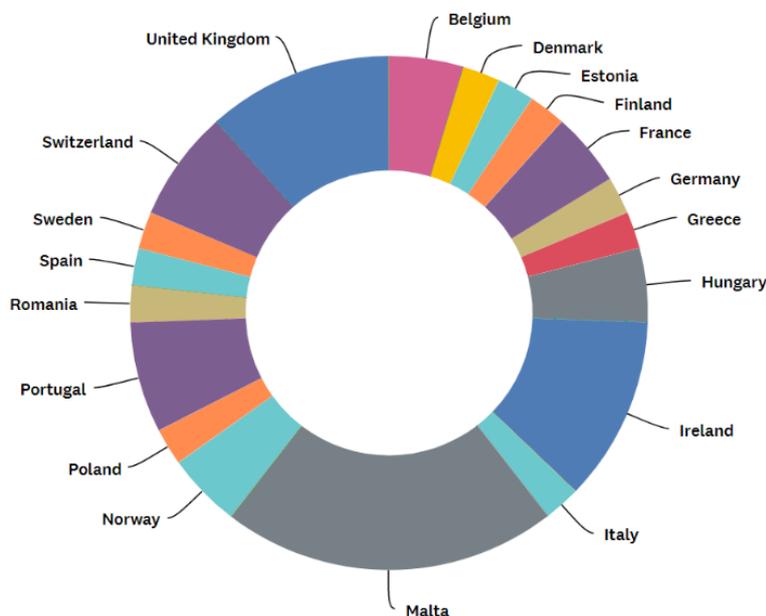
Amongst **individual respondents**, the majority were patients with chronic or long term condition(s) (86%) and 14% identified themselves as family/informal carer.

Participants were spread across age categories, with moderate peaks of respondents between 31 and 45 years old and between 46 and 60 years old. Of all respondents, 21% were aged 16-30. The gender balance of the individual respondents was about 70% women and 30% men.

Individual respondents identified with a range of disease areas, however a large majority of participants were neurological patients (46%), closely followed by patients with autoimmune disorders (30%). Respondents who selected the option “other” (12%) explained that they have multiple conditions and belong to more than one category.



*Geographical distribution of individuals responses*



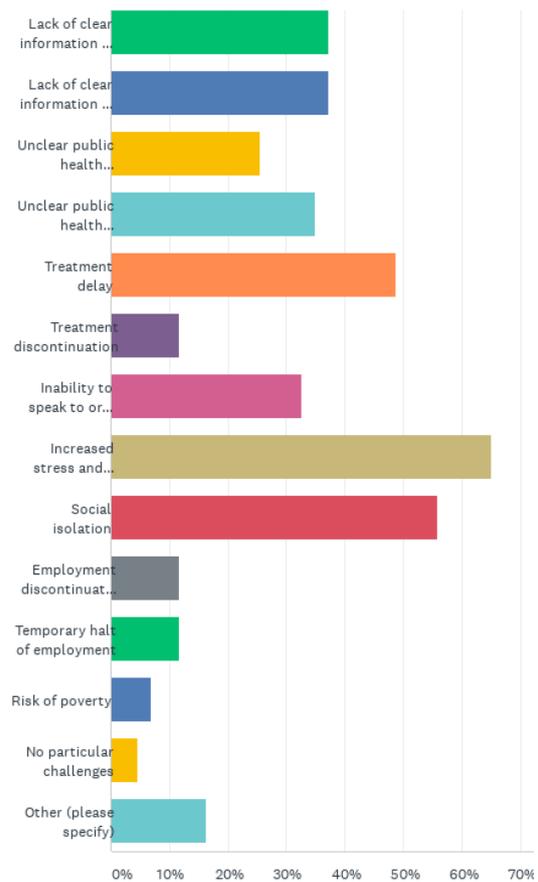
Individual responses from 19 different European countries have been analysed in this report. Responses from individual patients or carers were unevenly spread between countries, with 9 respondents residing in Malta. Ireland and the United Kingdom account for 5 responses each. Portugal and Switzerland yielded 3 responses each and Norway, Hungary, France and Belgium yielded 2 each. The remainder of countries shown in the chart below yielded 1 response.

Then, our survey was divided into several main sections. Below, we present the summary results of each.

### 1.1.1 CHALLENGES FACED BY PATIENTS

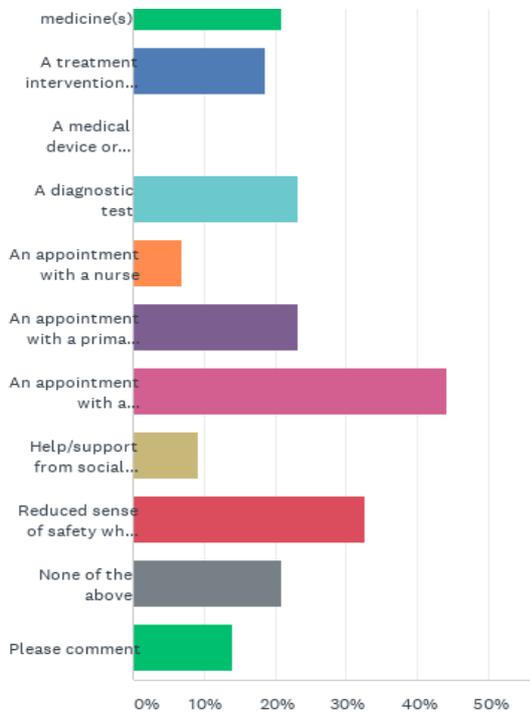
Participants were asked to indicate what challenges, if any, they had faced due to the pandemic, indicating all applicable answers. Of all individual respondents, **95% have experienced challenges due to the pandemic**. A majority of individual respondents have faced **increased stress and anxiety** due to the pandemic (65%). This is closely followed by **social isolation** (56%). The detrimental impact of the pandemic on timely access to treatment is also confirmed by the results of our survey. Almost half of respondents have faced **treatment delay** (49%) and 12% have experienced treatment discontinuation. Further results relating to health care accessibility can be found below. Another important challenge faced by patients was the **lack of clear information and communication** from national authorities (37%) and healthcare providers (37%) on the availability and accessibility of healthcare services and treatments during the pandemic. Further results relating to information to patients can be found below. One third of individual respondents (33%) were unable to speak to or consult their healthcare professional(s). The impact of the pandemic on the **employment of individual respondents** was also significant, with 12% experiencing employment discontinuation and another 12% experiencing temporary halt of employment. In total, almost one quarter of respondents' employment has been negatively affected by the pandemic. Respondents indicating "other" explained that being a patient as well as a carer during the pandemic has signified a double burden, leading to deterioration of the patient and carer's health status and ability to work and therefore negatively affecting the family's economic situation.

Challenges faced by patients due to the COVID-19 pandemic



### 1.1.2 ACCESS TO HEALTHCARE

*Delays and obstacle faced by patients accessing health services or products*



Two questions of the survey addressed accessibility of healthcare directly. When asked how difficult or easy it has been to obtain the healthcare and services needed since the beginning of the pandemic, a majority of individuals (51%) indicated “moderate”, 19% indicated “difficult”, 19% “easy”, 9% “very difficult” and 2% “very easy”.

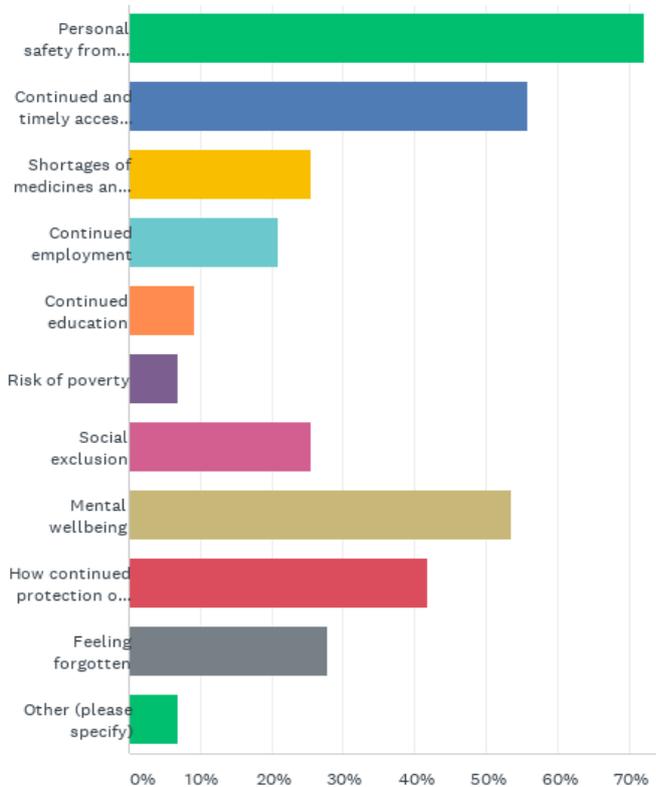
Participants were also asked whether they had experienced a significant delay or obstacle in accessing a given service or product. Close to half of respondents (44%) have experienced a significant **delay or obstacle in accessing an appointment with a specialist**, followed by one third having experienced a **reduced sense of safety when visiting healthcare facilities** (or HCPs) for example due to COVID-19 infection risk. A significant delay or obstacle in accessing an appointment with a **primary care doctor or a diagnostic test** had been experienced by 23% of respondents each. For 21% of participants, none of the options proposed were applicable. More than one fifth (21%) of respondents had experienced a significant **delay or obstacle in accessing their medicines**. Fear of medicine shortages was also expressed. 19% had experienced a significant **delay or obstacle in accessing treatment intervention**, such as surgery or other procedure. One patient from France explained having to wait 2.5 months for a biopsy to check whether cancer had come back. A lower percentage of respondents experienced a significant delay or obstacle in **accessing help/support from social services** (9%) and an **appointment with a nurse** (7%).

### 1.1.3 PATIENTS’ CONCERNS

In addition to the challenges they have faced, participants were asked what their main COVID-19 related concerns were, at the time of responding to the survey. They were asked to indicate all proposed responses that applied. **A large majority of patients (72%) indicated that personal safety from COVID-19 was their main concern**. This confirms the significant reduced sense of safety when visiting healthcare facilities (or HCPs), experienced by one third of individual respondents as explained above. **Continued and timely access to healthcare professionals** and regular consultations (56%) in

addition to **mental wellbeing** (53%) were indicated as main concerns for over half of respondents. Close to half of respondents (42%) were concerned about how continued protection of patients during **deconfinement and relaxation of restrictive measures** is managed in society. In a statement issued in April during the first ‘lockdown’, EPF warned governments to give serious thought and priority to the protection of patients with chronic conditions, when exiting confinement.<sup>1</sup> Almost a third of respondents (28%) indicated **feeling forgotten** as a main concern, closely followed by **social exclusion** (26%). Over one quarter of respondents (26%) indicated that **shortages of medicines** and technologies were a main concern. Over one fifth of respondents (21%) highlighted continued **employment** as a main concern. A lower percentage indicated continued **education** (9%) and **risk of poverty** (7%) as main concerns.

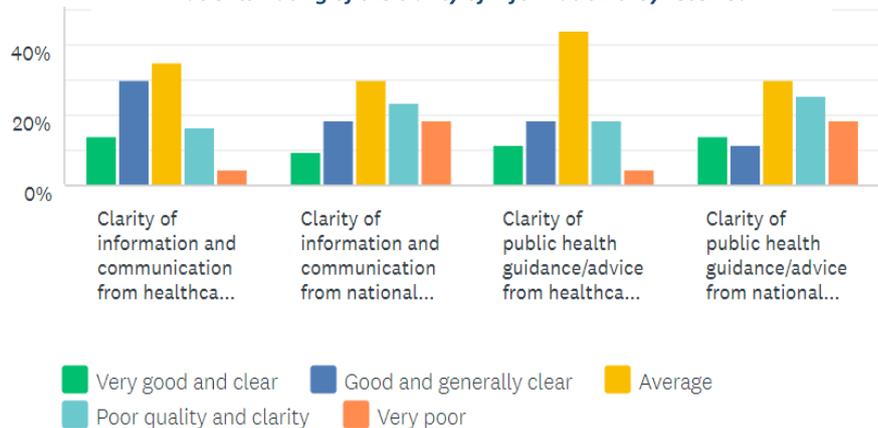
*Patient’s major COVID-19 concerns at the time of responding*



#### 1.1.4 INFORMATION TO PATIENTS

Participants were asked to rate the clarity of information and communication from both healthcare providers and national authorities on the availability and accessibility of healthcare services and treatments as well as the clarity of public health guidance/advice from healthcare providers and from national authorities.

*Patients’ rating of the clarity of information they received*



In terms of the **clarity of information and communication from healthcare providers** on the availability and accessibility of healthcare services and treatments, a majority of participants (35%) indicated “average”, closely followed by 30% who indicated “good and generally clear”. In terms of the **clarity of information and communication from national governments** on the availability and accessibility of healthcare services and treatments, most participants (30%) indicated “average”, followed by 23% who indicated “poor quality and clarity”. Regarding **clarity of public health**

<sup>1</sup> <https://www.eu-patient.eu/COVID-19/epf-covid-statements/epf-statement-on-the-covid-19-pandemic/>

**guidance/advice** from healthcare providers, almost half of participants indicated “average”, followed by “good and generally clear” (19%) and “poor quality and clarity” (19%). Regarding clarity of public health guidance/advice from national governments, a majority of participants indicated “average”, followed by “poor quality and clarity” (26%) and “very poor” (18%).

Following this question, participants were asked to comment on their answers and/or provide examples. Several participants criticised the fact that information was changing on a daily basis with no notice, contributing to confusion. Such rapidly changing information has put an additional burden and challenge on patients’ in organising their medical schedule, not mentioning additional stress. Furthermore, no or very little information on longer term planning from healthcare providers or national governments has meant that patients have been unable to take decisions regarding their healthcare in a fully informed way.

**“I am postponing elective hospital visits (dentist, dermatologist, regular screenings) because of fear of infection. However, I am worried the infection risk will get even higher/ambulatory services get closed again and I might end up with an acute problem because of postponing these visits, making it even worse in the future than now.”**

- Patient, Hungary

Others commented that policies were based on anecdotal evidence. Another example given was that new circuits have been created within hospitals for COVID patients, but there are no clear indications of circuits for non-COVID-19 patients.

Finally, when asked to share thoughts on how the pandemic had impacted their physical and mental health in ways not covered by this survey, many respondents shared negative experiences. On mental health, several mentioned “insecurity” and “feeling unsafe” in crowded places and/or public transport. In a similar vein, one respondent pointed out that due to her/his chronic disease wearing a mask makes it even more difficult to breathe. Another patient referred to the difficulties of being his brother’s carer, and, at the same time, being COVID-19 infected.

Another patient said that due to the pandemic the physiotherapists’ visits had to be halted, to the detriment of her/his chronic disease.

## 1.2 DISCUSSION

Since the beginning of the pandemic, EPF has called for easy and timely access to healthcare for patients, not hindered by misinformation or other barriers. At the time when this survey was distributed, there were important differences in healthcare accessibility experienced by European patients during the pandemic. **The results of this survey show that there is significant room for improvement for both healthcare providers and national authorities on the clarity of information, communication and public health guidance.** These results indicate that clarity of information, communication and public health guidance from healthcare providers has been perceived as slightly better than the clarity of information, communication, and public health guidance from national governments. EPF recommends involving patient organisations<sup>2</sup> in the development and deployment of communication strategies as well as healthcare providers.

<sup>2</sup> <https://www.eu-patient.eu/COVID-19/epf-covid-statements/epf-statement-on-the-covid-19-pandemic/>

Health system responses to the crisis have in some locations resulted in changes that patients have hoped for many years would happen – such as: virtual consultations, patients and professionals using online tools to communicate information, physicians’ access to health records from offsite, and home delivery of treatment and medications or local pharmacy access. This is unfortunately not yet the norm and too few patients with chronic conditions are benefitting from these alternative solutions. The results of this survey show many patients feel vulnerable and would welcome solutions that enable them to access healthcare services, such as consultations with healthcare professionals, from their own homes when needed.

Many national patient organisations have reported challenges in both accessing treatment and medical consultation and have proposed solutions to their governments. In keeping patient safety as a top priority, in Spring 2020 EPF called on Member States to ensure that accessible and affordable telemedicine services are made available to everyone in Europe.

To date, we have not seen a systematic collection or sharing of “best practice” alternative access solutions (for example virtual consultations, automatic prescription renewals etc.). This is one area, among many, where the European Commission can support Member States, with the involvement of patient organisations.

Digital transformation is already happening. But we believe that in order to bring real value, Europe’s future digital health tools and systems should start from patients’ priorities and be co-developed with patients. Digital health is an area where co-design is not yet well developed. Driving a person-centred transformation in this area is one of EPF’s core priorities for the next years and will be the theme of the [2021 EPF Congress](#).

## 2. Patients’ organisations survey

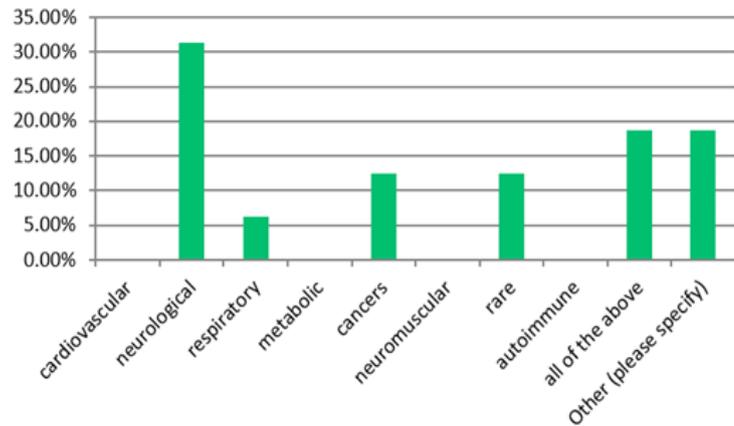
### 2.1 SURVEY RESULTS

European and national organisations accounted for the majority of responses from **patients’ organisations** (43% each). A minority of responses came from regional or local organisations. **Altogether, 57 patient organisations responded to this survey.**

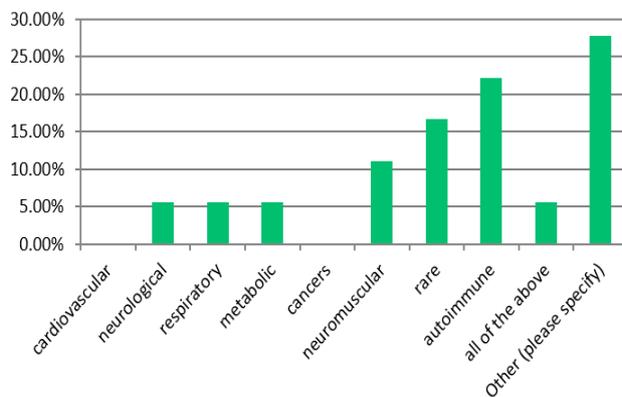
The majority of European organisations that responded to our survey are based in Belgium, followed by Greece, Italy and the Netherlands. National patients’ organisations that responded to the survey are based in Greece (5 responses), Malta (4 responses), Romania and Belgium (2 each), Bulgaria, Finland, the Netherlands, Slovenia and Sweden (1 response each).

All disease areas were covered by responding European organisations, with 31% of organisations representing patients with neurological disorders and 19% of organisations covering all disease areas listed. Responding European organisations who selected the option “other” (19%) explained that they cover multiple disease areas or specified incontinence issues, pelvic pain and stroke.

*Disease areas of responding European patients’ organisations*



*Disease areas of responding national patients’ organisations*

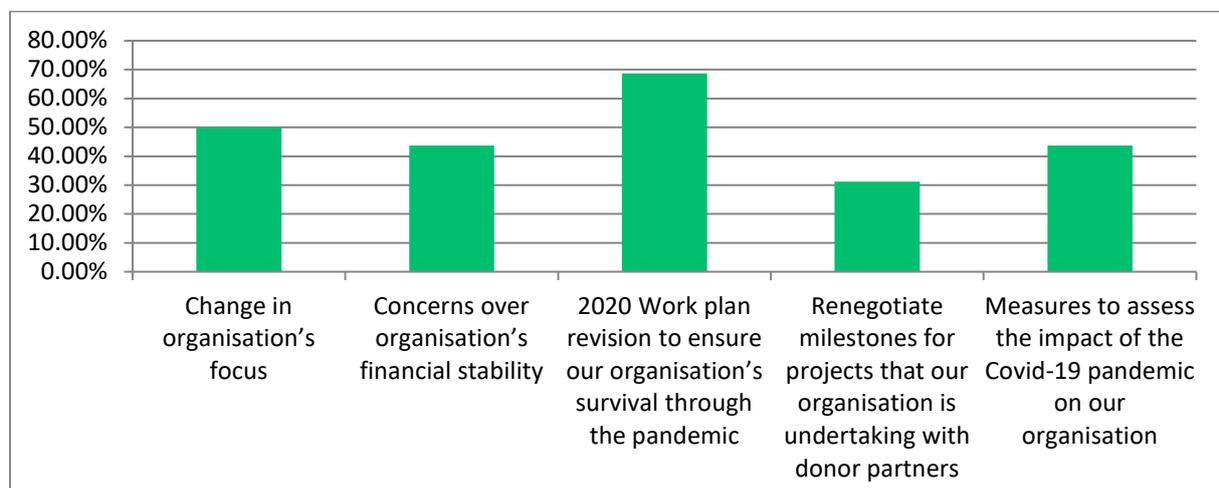


The majority of disease areas listed were covered by responding national patients’ organisations, with 28% of organisations selecting the option “other”, specifying several but not all disease areas listed, HIV, psychiatric and mental health, palliative care for cancer, motor neurone disease, end life cardiac, liver and renal failure and asthma and allergy. The option “other” was closely followed by autoimmune disorders (23%) and rare diseases (17%).

### 2.1.1 FUNCTIONING OF PATIENTS’ ORGANISATIONS

Patient organisations were asked to indicate which changes if any, they had to undergo due to the pandemic, indicating all applicable answers. Of all responding organisations, **69% had to revise their 2020 work plan** to ensure the survival throughout the pandemic, and **50% of respondents had to change the organisation’s focus**. Some 44% of the responses point at **concerns over financial stability**, and 44% implemented **measures to assess the impact of COVID-19**.

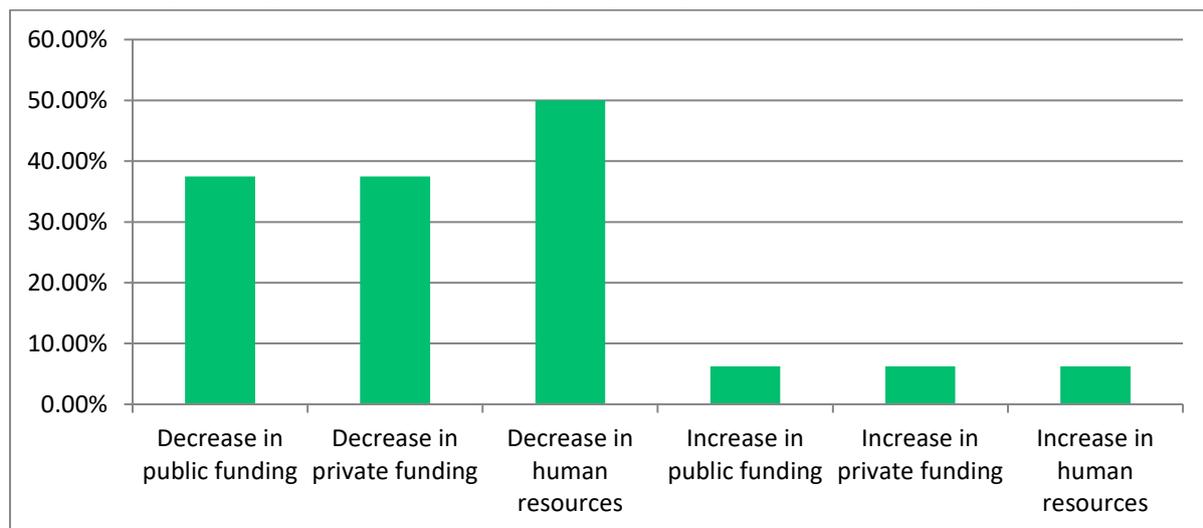
*Changes that patient organisations have faced due to the pandemic*



Regarding the impact of the pandemic on future funding, 38% of the responding organisations foresee a **decrease both in private and public funding**. Some 50% of the respondents also believe that there will be a **decrease in human resources**.

Organisations whose funding depends on the industry do not anticipate major changes. However, those that are membership-funded expect a decrease, as membership fees are calculated on the basis of members’ income (which is presumed to fall). These difficulties in finding many organisations foresee translate in difficulties maintaining staff members.

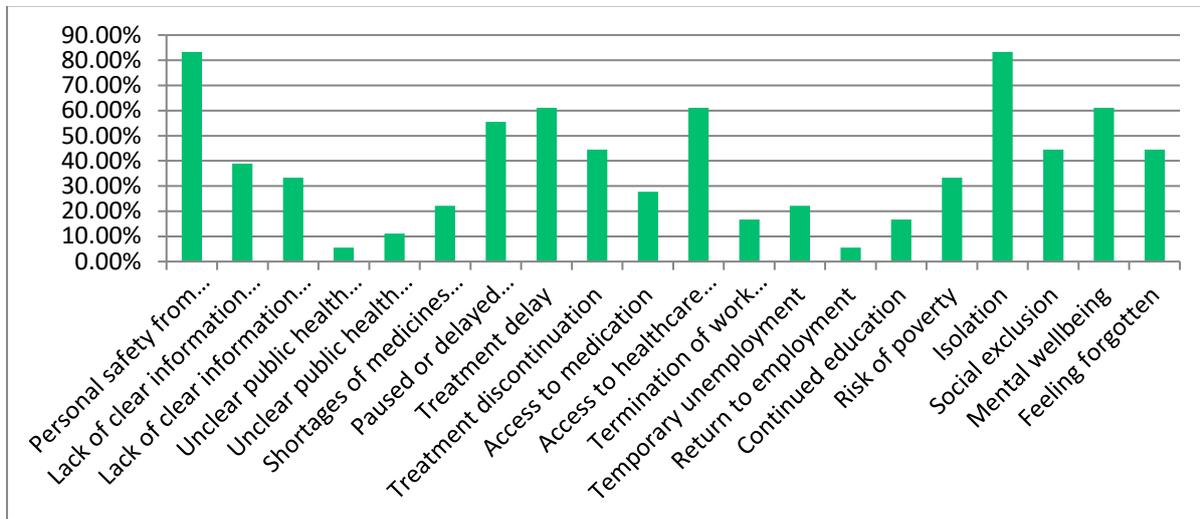
*Extent to which patient organisations think that their future funding (i.e., 2021 onwards) will be affected by COVID-19*



When asked which service proved to be most popular during the pandemic, most organisations highlight the possibility of **organising online webinars** for patients and other interested stakeholders. These proved to be a useful tool for raising awareness on how COVID-19 impacted their activities and/or for reaching out to people who could not have been met face-to-face otherwise. Other digital services such as **online training** and **podcasts** were mentioned as well.

Then, responding organisations were asked what are the main COVID-19-related concerns that they have for the patients they represent. Some 88% of the organisations that replied mentioned personal safety from COVID-19, followed by treatment delay (75%) and paused or delayed diagnosis (63%); and isolation (69%).

*At the point of answering to this survey, the main COVID-19-related concerns that responding organisations had of the patients that they represent*



*- Personal safety from COVID-19; - 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.*

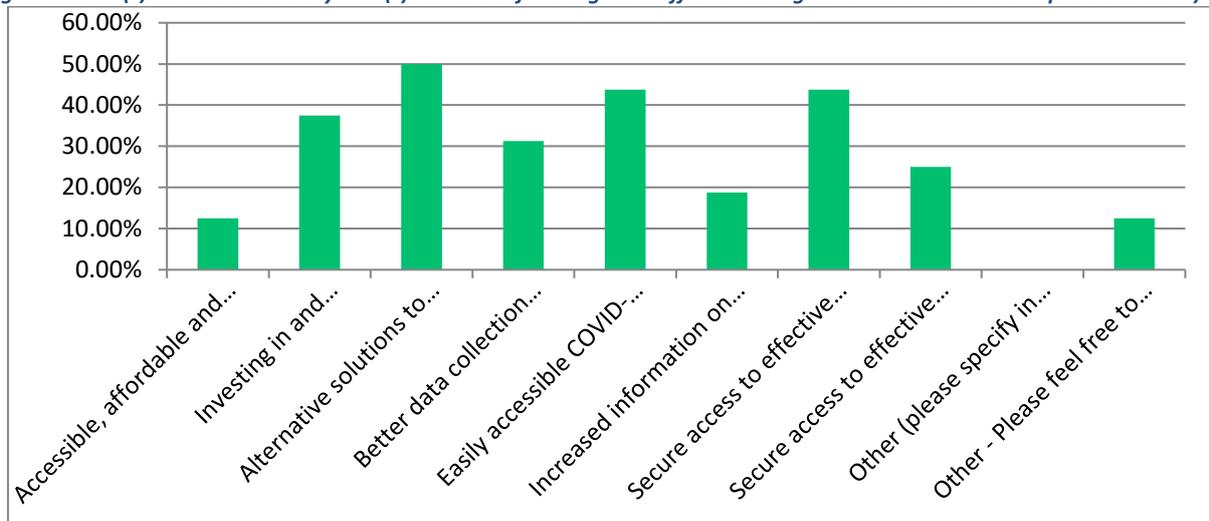
### 2.1.2 PROTECTION MEASURES

During the pandemic, EU governments tried to put in place some protection measures aimed at people with chronic conditions and/or vulnerable. However, these often fell in the second place, as all the attention was given to the handling of the pandemic, particularly in the early stages. When asked about how they found these measures, 50% of respondents replied that they were not appropriate and that they had a negative impact on the patients they represent, whereas only 38% of the respondents considered them partially appropriate (i.e., having a mild to positive impact for the patients they represent). Only 12% of the responding organisations considered them appropriate and appreciated by their represented patients.

In the comments section, some organisations highlighted that due to the pandemic and the lack of efficient protection measures, care had to be delayed, essential services cancelled, there was a lack of targeted advice, and so on.

Participating organisations were also asked, at the time they were responding to the survey, what were the three most important things that their national government(s) and health care system(s) should be focusing their efforts on.

*At the time of filling in this survey, what were the three most important things that the respondent's national government(s) and health care system(s) should be focusing their efforts on. Organisations could 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.

The majority of respondents selected “**alternative solutions to access treatment/medicines, e.g. home delivery or pharmacy pickup**” (50%), followed by “**secure access to effective and safe COVID-19 vaccine**” and “**easily accessible COVID-19 testing framework and facilities**” (both selected by 48% of the respondents). 38% of responding organisations also selected “**investing in and improving healthcare capacity**”.

Those who responded “other”, highlighted that all the above-mentioned points are important, but that the focus should be on the continuation of services; as well as on the importance of the COVID-19 test and tracing measures.

Finally, building on the former question, participating organisations were also asked for their most important recommendation(s) to the EU on improving the management of the COVID-19 crisis and for ensuring the protection of patients with chronic conditions. Participants highlighted the **need to involve patients in the recovery planning, investing more in healthcare** (which is essential for the future of European citizens), **encouraging policy makers to understand that chronic diseases do not stop with the pandemic** – hence, making sure that treatments cannot be delayed, and the importance of **betting coordinating public health measures** (e.g., COVID-19 testing and tracking) at the EU level.

### 2.1.3 INVOLVEMENT OF PATIENTS’ ORGANISATIONS IN THE MANAGEMENT OF THE PANDEMIC

Following up on the previous set of questions, participants were also asked, based on their experience, to what extent patients and their representatives had been involved in the management of the pandemic. The majority of the respondents (63%) indicated that there had been no patient involvement at all (patients were not consulted at any stage, and people with chronic conditions were

left aside from the pandemic management decision-making process). Another 19% of the respondents pointed to very little meaningful patient involvement (e.g., patient organisations had been contacted by health authorities and asked to disseminate information with their members). Only 12% of respondents pointed to good patient involvement (e.g., patients were represented within their country's crisis task force, such as having two patients and their organisations involved in the reorganisation of healthcare during lockdown).

## 2.2 DISCUSSION

These survey results summarised in the section above, indicate that the pandemic had a huge impact not only on the financial stability of patient organisations, but also on the way they work.

For example, several organisations highlighted as comments to several questions that they had to fully digitalise their day-to-day operations, including moving face-to-face meetings and training to virtual platforms. There seems to be a trend by which patient organisations are increasingly digitalising their advocacy activities, and their liaising activities with the patients they represented. For some organisations, this trend was both an opportunity to cut on costs of face-to-face meetings (virtual sessions are often referred to as cheaper), as well as for mapping new advocacy/policy angles and opportunities.

Regarding the funding of patient organisations, the findings show that patient organisations are financially vulnerable, and those funded primarily by their members are particularly vulnerable. Patient organisations also face new challenges in digitalising their operations. This finding reinforces our long-standing call for a sustainable and ethical funding framework to support patient organisations' functioning, both at EU and national levels.

Finally, patient organisations say that governments should ensure patient's access to healthcare without disruptions, caused by the ongoing pandemic, or by any other reason. Patient organisations' responses confirm reports that treatment for many chronic diseases and most non-urgent surgeries were delayed and postponed. As some commented, unfortunately, early cancer screenings and other similar activities were postponed, too. All of these took a toll on patients living with chronic diseases.

## 3. Recommendations

From these first survey results we can identify some broad recommendations to policy-makers and healthcare providers when considering both short- and longer-term responses to the COVID-19 pandemic, including making contingency plans and formulating strategies for future crisis preparedness.

### 3.1.1 SUPPORT FOR PATIENTS LIVING WITH CHRONIC DISEASES

- Involve patients with chronic conditions and their carers in co-designing measures, including actions to reduce patients' stress, feelings of isolation, and protect their personal safety (i.e., reducing their risk of infection) and mental health.
- Establish clear and easy-to-follow communication channels to be used by patients for reaching out to their healthcare professionals.
- Ensure clarity, timeliness and accessibility of public health communications.

- National authorities should accelerate the ongoing digitalisation of their healthcare systems in co-creation with patients and ensure equity in access to digital services.
- Whenever a health crisis occurs, healthcare systems' managers should do all that is possible to not delay treatment/interventions aimed at patients living with chronic diseases. As these patients cannot put their diseases "on hold", nor can their needs of healthcare be postponed and/or cancelled. That has devastating long-lasting effects for patients and often cannot be reversed. Ensuring health system capacity requires long-term investment and stress-testing with patients' needs at the centre.

### 3.1.2 SUPPORT FOR PATIENT ORGANISATIONS

- Ensure sustainable public funding of European and national patient organisations. Their survival and ability to function is essential to ensure meaningful patient input into improving health systems' quality and resilience.
- Collaborate with patient organisations to better handle health crises in the aftermath of the COVID-19 pandemic. These organisations occupy a key position between patients with chronic conditions and decision makers, both at the organisation and system level. They are key positioned to channel patients' needs and expectations into policymaking and health management.

### 3.1.3 LIMITATIONS

The limitations of this survey stem, mostly, from the small number of respondents and the imbalance between different countries. Thus, no generalisations can be drawn from the results. Nevertheless, results are in line with previous EPF surveys and member consultations, and we can therefore consider them reasonably valid. This survey yields important insights into how patients and patient organisations across Europe have experienced the impact of the COVID-19 pandemic. In the next edition, EPF will follow up on key themes and concerns identified in this survey.

## 4. Concluding remarks

Patient organisations have been very active throughout the COVID-19 pandemic, monitoring the evolution and shortcomings of European/national healthcare systems in the covered disease areas. This survey may serve as the testimony that, even as funding opportunities decreased, and their activities became more difficult due to the ongoing pandemic, they continued working at the forefront of advocacy – each within its geographic realm and disease-areas – advancing patients/carers' interest.

The results of this initial survey will be used by EPF to support its ongoing European initiatives and advocacy activities relating to COVID-19. Moreover, a second edition of this survey will follow.