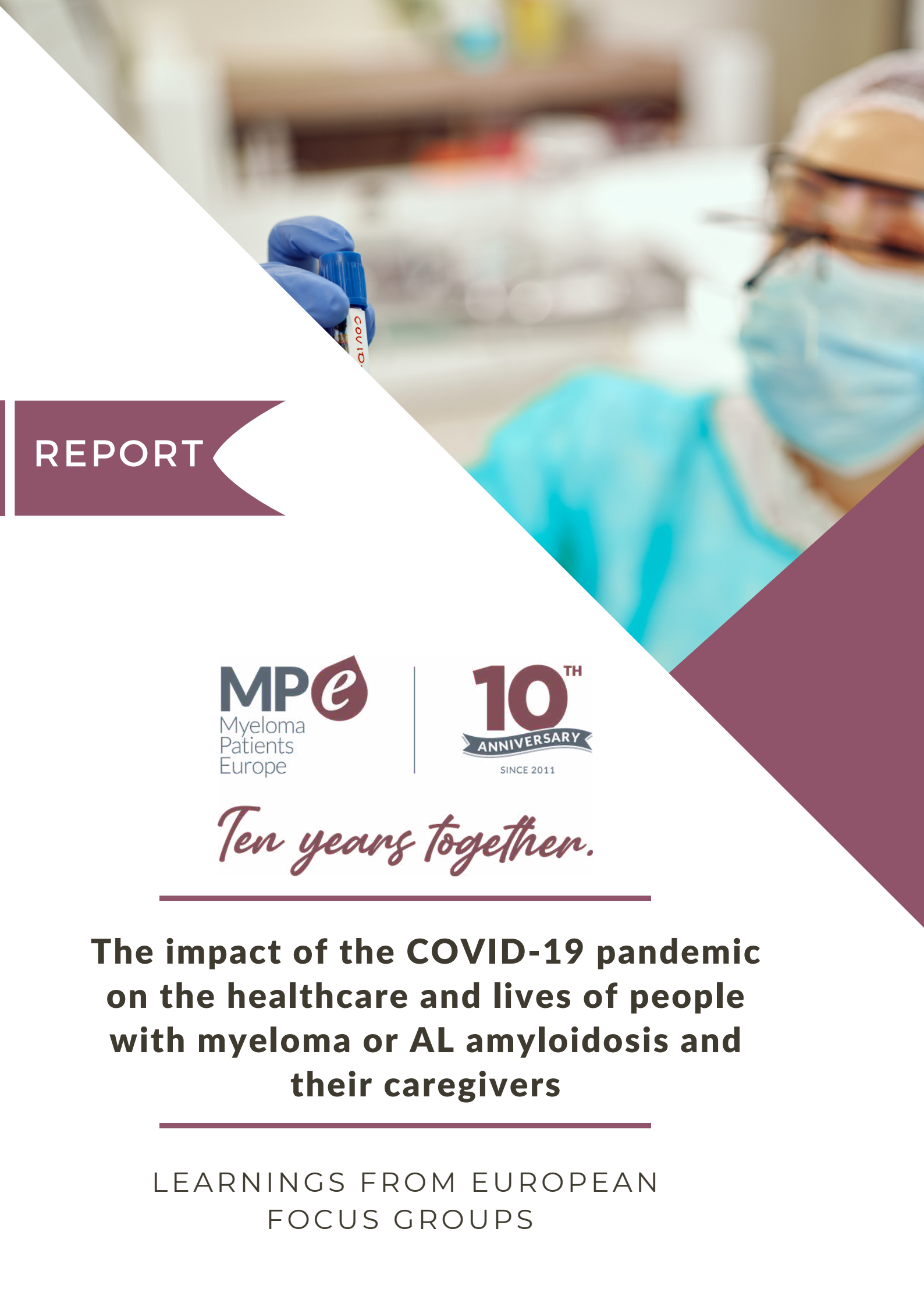




REPORT



Ten years together.

The impact of the COVID-19 pandemic on the healthcare and lives of people with myeloma or AL amyloidosis and their caregivers

LEARNINGS FROM EUROPEAN
FOCUS GROUPS

Edition: Myeloma Patients
Europe and Excerpta Médica.
June 2021

Myeloma Patients Europe AISBL
Avenue Louise 149/24
1050 Brussels - Belgium

www.mpeurope.org
info@mpeurope.org

MPe
Myeloma
Patients
Europe

FOREWORD

No organisation or individual could have anticipated the outbreak of Covid-19, resulting in a global pandemic and huge changes to daily life, business, and healthcare. In early 2020, MPE launched our COVID-19 Outreach Workstream to understand and respond to the needs of MPE members and the patient community.



Ananda Plate
CEO, Myeloma Patients Europe (MPE)

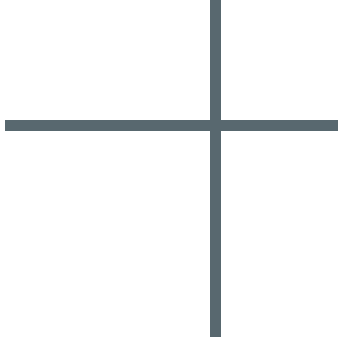
As of this publication the pandemic endures, and we do not yet know the myriad long-term effects it will have on patients and carers. This report provides insights into the patient and carer experience during COVID-19, its impact on diagnosis and treatment, effects on quality of life and psychosocial needs, and prompt access to vaccines, or lack thereof. The findings from this report can help identify potential needs of myeloma and AL amyloidosis patients, existing gaps in knowledge and services, and inequalities in access, which will be used to support MPE's ongoing efforts to advocate for improved treatment, care, and access for the European patient community. Also, we hope that this report can be a valuable resource for patient organisations advocating at the national level.

I am very grateful for the patients, carers and advocates who shared their experiences with us. Whilst some learnings, including the impact on both myeloma treatment and other healthcare services, as well as the significant psychosocial toll of the pandemic, were very concerning, there were some positives, such as the ease of telemedicine and the confidence in the vaccines. We hope these results will help healthcare professionals, advocates, and the patient community identify the long-term needs of patients beyond the current pandemic and support the creation of a roadmap for better patient care during future public health emergencies.



INDEX

• Foreword	2
• Introduction	4
• Impact of the COVID-19 pandemic and restrictions on myeloma and AL amyloidosis treatment	7
• Impact of the COVID-19 pandemic and restrictions on access to wider healthcare services	13
• COVID-19 vaccination	15
• Emotional and psychological impact of the COVID-19 pandemic and restrictions	20
• Sources of support	26
• Conclusions and recommendations	28
• Acknowledgements	30



INTRODUCTION

Myeloma Patients Europe (MPE) is an umbrella organisation representing 49 myeloma and AL amyloidosis patient groups and associations from across Europe and further afield. Our mission is to provide education, information, and support to members and to advocate at European, national, and local levels for the best possible research and equal access to the best possible treatment and care. Together, we support thousands of patients with myeloma and AL amyloidosis, as well as their caregivers, every day.

As the SARS-CoV-2 (COVID-19) pandemic unfolded in 2020, we became aware that the pandemic, and the restrictions imposed, were impacting the healthcare and lives of people with myeloma and AL amyloidosis, and their caregivers. Findings from a small UK study have suggested that when myeloma patients caught COVID-19 in early 2020, they were more likely to die than members of the general population who contracted COVID-19 [Cook G, et al. *Br J Haematol*. 2020].

Through our COVID-19 Outreach Workstream, we began research (surveys and focus groups) to learn more about the impacts of the COVID-19 pandemic and related restrictions. In this report, we summarise the results of a series of semi-structured focus groups conducted to collect personal experiences and broader insights from patients and caregivers.

METHODS

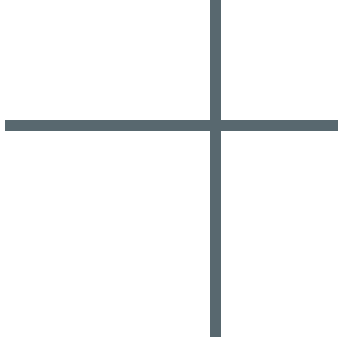
AIMS

In March 2021, MPE held four online focus groups in Europe to collect the views and experiences of patients with myeloma and AL amyloidosis and their caregivers regarding the COVID-19 pandemic. Our aims were to:

- discover how the COVID-19 pandemic, as well as restrictions imposed because of the pandemic, have affected the healthcare and lives of people with myeloma and AL amyloidosis and their caregivers
- use these insights to identify how MPE and member organisations can support the unique needs of people living with myeloma and AL amyloidosis

PARTICIPANTS

In total, 15 patients and two caregivers took part in our focus groups. Thirteen patients had myeloma and two had AL amyloidosis. One of the caregivers was an asymptomatic carrier of hereditary transthyretin amyloidosis (also known as TTR amyloidosis). The participants were from Spain (n = 6), the UK (n = 2), Belgium (n = 2), Germany (n = 2), the Netherlands (n = 1), Iceland (n = 1), Israel (n = 1), Poland (n = 1), and Romania (n = 1). Eleven patients had been diagnosed within the last few years, whereas others had been living with their disease for a decade or longer. Ten patients were receiving active treatment for myeloma or AL amyloidosis during the COVID-19 pandemic, while others were in remission. Approximately 60% of participants were male.



FOCUS GROUPS

Three focus groups were held in English and one was held in Spanish. Each focus group lasted 1.5 to 2 hours. Participants answered questions both from their personal experiences during the COVID-19 pandemic and insights gained through the patient organisations of which they are members.

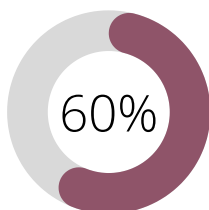
Each focus group was facilitated by one or two MPE representatives. In addition, a haematologist-oncologist attended one focus group for learning purposes. Using open-ended questions, the moderators guided the discussion through five topics:

- Impact of the COVID-19 pandemic and restrictions on myeloma and AL amyloidosis treatment
- Impact of the COVID-19 pandemic and restrictions on access to wider healthcare services
- COVID-19 vaccination
- Emotional and psychological impact of the COVID-19 pandemic and restrictions
- Sources of support

HOW DID THE COVID-19 PANDEMIC AND RESTRICTIONS AFFECT PATIENTS' ACCESS TO TREATMENTS FOR MYELOMA AND AL AMYLOIDOSIS?

AVAILABILITY OF TREATMENTS

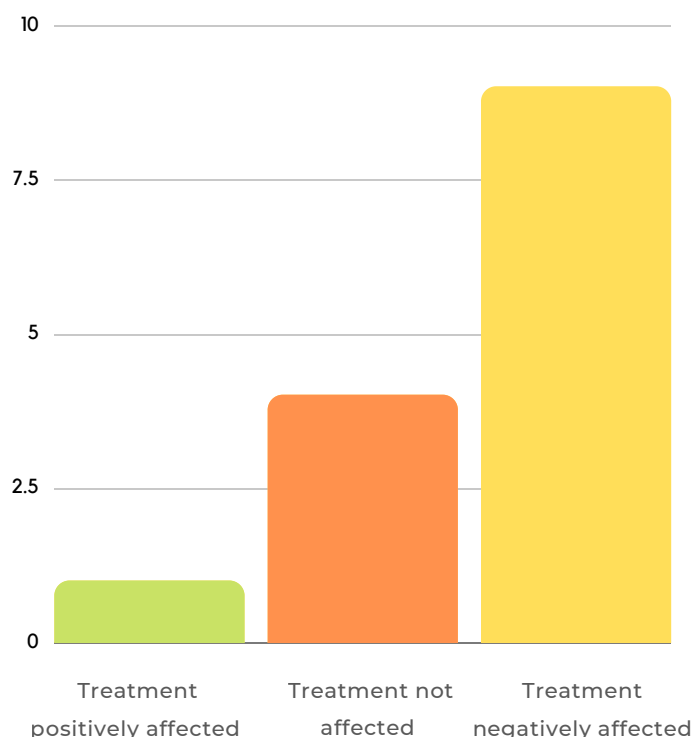
Over half of the patients in our focus groups said their treatment or another patient's treatment for myeloma or AL amyloidosis was affected during the COVID-19 pandemic. Invasive tests and treatments were more often delayed than injections/infusions or oral medications. Some patients' care continued as normal, albeit with some check-ups being conducted by telephone or video call rather than in person.



60% of participants reported that treatment for myeloma or AL amyloidosis was negatively affected during the COVID-19 pandemic

EFFECT OF THE COVID-19 PANDEMIC ON TREATMENT FOR MYELOMA/AL AMYLOIDOSIS (OF 15 PATIENTS WHO SHARED THEIR EXPERIENCE)*

*Some of these responses are based on personal experience, while others are based on the experiences of other patients in the participant's network.



Three people said that medicines given in hospital (by infusion or injection) were delayed due to the COVID-19 restrictions. Sometimes, the frequency of these treatments was reduced. In contrast, most patients taking oral medicines (tablets) reported that their treatment continued as normal.

“

“I am on Revlimid and this is oral, so this has not been affected... the only thing that was impacted was that I was supposed to do a bone marrow biopsy... around April last year. So, we rescheduled it for around August.” Patient 1

Seven participants said their or another patient’s invasive procedure (such as a bone marrow biopsy or stem cell transplant) had been delayed. These procedures went ahead after approximately 1–6 months, once doctors and patients felt it was safe to do so.

One patient reported an improvement in her treatment due to the pandemic restrictions. Her 4- to 5-hour long infusions of daratumumab in hospital had been switched to subcutaneous injections with fewer side-effects.

ACCESS TO CLINICS AND HOSPITALS

Access to clinics and hospitals for myeloma or AL amyloidosis treatment differed between countries. Patients in Belgium said that hospital services for myeloma or AL amyloidosis care continued as normal.

“

“In Belgium, it’s very well organized. I think for the myeloma treatment, you get your treatment regardless. So, there is no hold-up anywhere.” Patient 2



However, patients in Romania, Poland and Scotland reported access issues, including:

- Hospital closures or reduced capacity
- Not being able to make appointments as far in advance as usual
- Reduced ability to travel and find accommodation, affecting hospital visits further away from home
- A requirement to complete a COVID-19 test before visiting the hospital

“

“Due to travel restrictions, of course patients had problems to get to the hospital... and to stay somewhere. Because the hospital hotels were closed and the other hotels were often suspended as well.” Patient 3

Three patients had been reluctant to go to hospital due to concerns over the risk of being infected with COVID-19. Some chose to delay routine check-ups (for example, bone scans) until they had received the COVID-19 vaccination.

“

“The first few months of the pandemic were very tense, because I would leave the house to go to the hospital quite scared and afraid of getting infected.” Patient 4

USE OF TELEMEDICINE

In most countries, it was common for patients to have some check-ups by telephone or video call, whenever this was appropriate.

“*Telemedicine is not that far [along] in Germany. Only a few doctors are doing that. It might be more advanced in other countries.*” Patient 5

Four out of five patients who gave their view on telemedicine were content with this approach. Some actively preferred videocalls as these minimised risks of catching COVID-19. However, one participant disliked telemedicine, finding it harder to have a discussion and remember their questions than in a face-to-face conversation.



4 out of 5 patients were content to use telemedicine, when appropriate

“*I was trying to minimise physical presence in the medical centre or here in the community...so I preferred the video meeting unless it was really critical for me to see her face-to-face.*” Patient 6

TAKING PART IN CLINICAL TRIALS

Four patients in our focus groups said they had taken part in a clinical trial during the COVID-19 pandemic. One clinical trial was paused, while others continued without delay.

One patient was preparing to receive experimental chimeric antigen receptor T cell (CAR-T) therapy for myeloma when the pandemic began. Her CAR-T therapy was delayed, which she believes led to the progression of her disease.

“

“In March I started the bridging treatment to undergo CAR-T. But the pandemic arrived, and everything stopped. That treatment was ruled out and I switched to a maintenance treatment. And that’s when the disease really progressed. I didn’t have any blood tests for a month, and in that time, everything went through the roof.” Patient 7

Another patient, who was receiving a combination of medicines in a clinical trial, said that the trial continued despite the pandemic and was well organised.

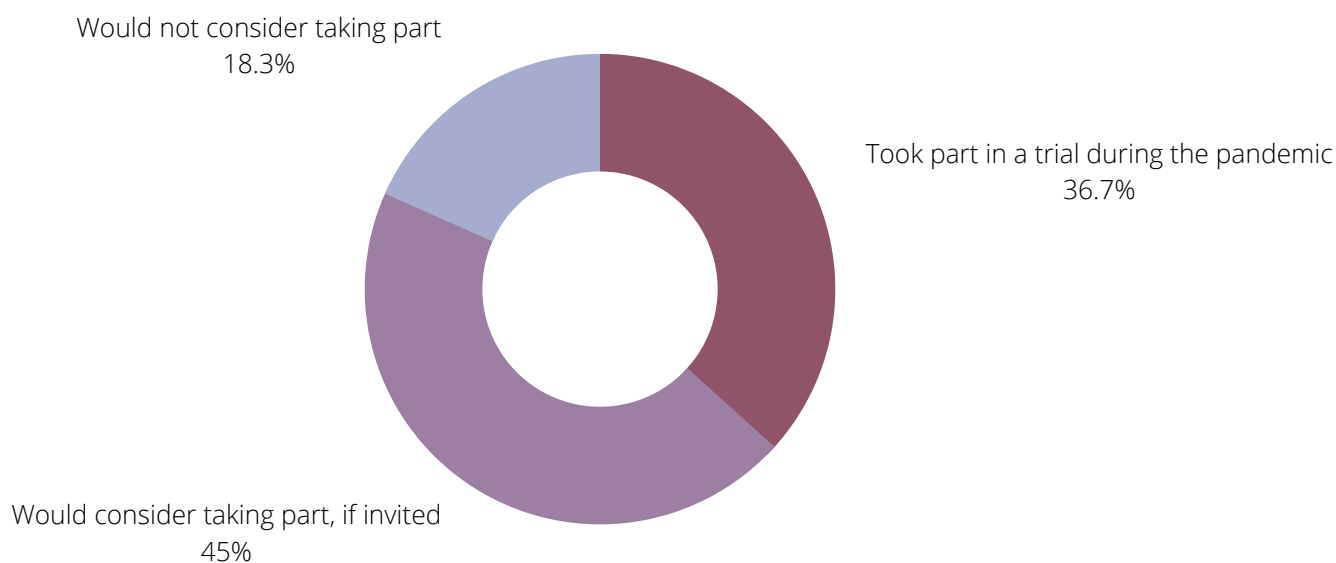
The pandemic also brought new opportunities to take part in research: one patient was taking part in a project to see how the COVID-19 vaccine affects patients with myeloma.



**4 out of 5 patients
continued their clinical
trial as planned during the
COVID-19 pandemic**

Although most participants did not have direct experience of clinical trials during the COVID-19 pandemic, five participants reflected on how they might feel if given the opportunity to take part in a trial. Each participant who considered the benefits and risks of trial participation as part of the focus group said that they would be happy to join a trial. Important factors in their willingness to participate were chances of response and survival, possible side-effects, and their family's views. One participant reported being motivated by the potential to further science and help others.

WILLINGNESS TO PARTICIPATE IN CLINICAL TRIALS DURING THE COVID-19 PANDEMIC (OF 11 PATIENTS WHO SHARED THEIR OPINION)



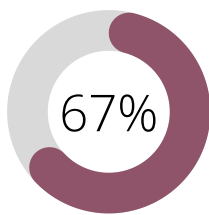
“

“Yes, I would go for it, even in COVID times. I would not have any problem doing that.” Patient 8

HOW DID THE COVID-19 PANDEMIC AND RESTRICTIONS AFFECT ACCESS TO WIDER HEALTHCARE SERVICES?

We asked participants whether they had experienced any problems accessing healthcare services beyond their myeloma or AL amyloidosis treatment. Their responses were mixed.

Of the nine people who shared their experiences, three were positive, saying they had not had problems. One patient felt it was easier to get an appointment than before, because fewer people were visiting the doctor. Another felt the punctuality of services had improved.



**of patients experienced problems with
accessing wider healthcare services during the
COVID-19 pandemic**

The remaining six patients had problems accessing certain services, including:

- Physiotherapy (for rehabilitation)
- Allergy clinic
- Ophthalmology (for cataract surgery)
- Dental services (for non-emergency dental care)
- Traumatology (for treating bone damage)
- Radiology (for a bone scan)

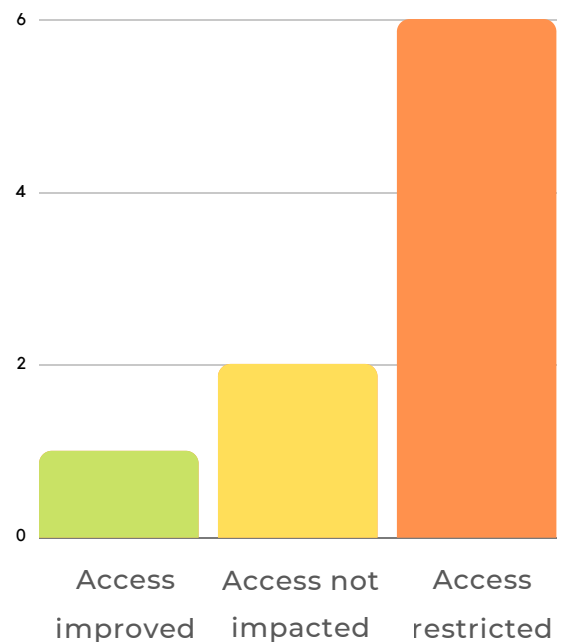
Many of these services were related to the treatment of ongoing complications from myeloma or AL amyloidosis. One patient reported that the lack of rehabilitation services affected their quality of life.

“

“The pandemic has brought these [rehabilitation] services to a halt, especially physiotherapy... I also have to have cataract surgery, but the ophthalmologist has told me that it is not the best time.” Patient 9

When asked how safe they felt visiting services, 10 patients reported feeling comfortable with the precautions being taken, while five patients mentioned concerns.

EFFECT OF THE COVID-19
PANDEMIC AND
RESTRICTIONS
ON ACCESS TO WIDER
HEALTHCARE SERVICES
(OF NINE PATIENTS WHO
SHARED THEIR EXPERIENCE)



WHAT ARE PATIENTS' AND CAREGIVERS' EXPERIENCES REGARDING COVID-19 VACCINATION?

VACCINE AVAILABILITY

The availability of vaccines against COVID-19 differed by country. Four participants had already received at least one COVID-19 vaccine dose. Two had received the Pfizer/BioNTech vaccine and 1 had received the AstraZeneca vaccine. They reported experiencing only minor side-effects.

“

“I was vaccinated on the 5th of February with the AstraZeneca vaccine. And I am receiving my 2nd vaccination this Saturday.... so I am very, very pleased.” Patient 10

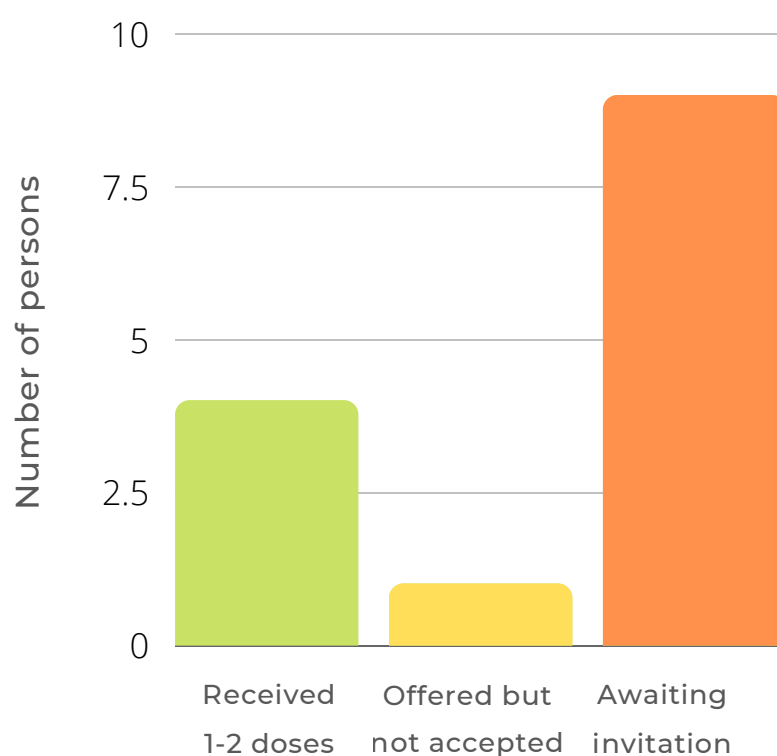
In many countries, national vaccination programmes had begun, and patients and caregivers were expected to be invited soon. However, patients in the Netherlands, Belgium, Spain, and Poland shared frustrations over the speed of roll out and lack of clarity over when they would be vaccinated. Some described the situation as a ‘mess’, ‘disaster’, or ‘chaos’.

“

“Well, the communication about the infection with the doctor is about zero. It's a real mess in Holland. I called about six times and I had to find out by myself. I have been waiting for 10 weeks now to get an invitation [for vaccination].” Patient 11



STATUS OF COVID-19 VACCINATION (OF 14 PATIENTS AND CAREGIVERS WHO CLARIFIED THEIR VACCINATION STATUS)



PRIORITY GROUPS

Participants were aware that myeloma and AL amyloidosis are thought to increase the risk of becoming seriously ill from COVID-19. In Spain, some patients had been advised to have the vaccine as soon as possible due to this risk, yet the vaccine was not available, causing frustration.

“My doctor told me a long time ago that haematology patients should be vaccinated as soon as possible, because the virus could affect us to a greater extent. Now I don't know when I'll get it.” Patient 7

In discussions about which groups of people were being prioritised for vaccination, it became clear that the approach differed by country. For example, in the UK and Israel, people were prioritised by their age and risk of getting seriously sick from COVID-19. However, our participant in Iceland understood that people were being called forward for vaccination based on their age only.

VACCINE BRANDS

The vaccine brands that patients had received (or were expecting to be offered) varied depending on national availability. Some participants were unclear about which vaccines would be available. In at least three countries (Iceland, Germany and Romania), vaccinations with the AstraZeneca vaccine had been paused while safety was reassessed.

It appeared that patients would not have a choice of which brand of vaccine they received. One patient had opted to delay accepting a vaccination invitation in the hope that a different brand would become available later.

“Here, the recommendation is that cancer patients should get Pfizer or Moderna. But none of these are available now. So, we are waiting... and AstraZeneca is available; however, not every doctor is recommending [this] for cancer patients.” Patient 3

INFORMATION ON VACCINES

The amount of information on vaccine availability, effectiveness, and safety differed greatly across Europe. Generally, patients in countries that were further ahead with their vaccination programmes reported receiving more information, especially just before they were vaccinated. Gaps or inconsistencies in this information were sometimes noted.

“Yeah, we have good information from the healthcare system. But OK, side-effects: they are still finding side-effects and there is not much talk about it.” Patient 12

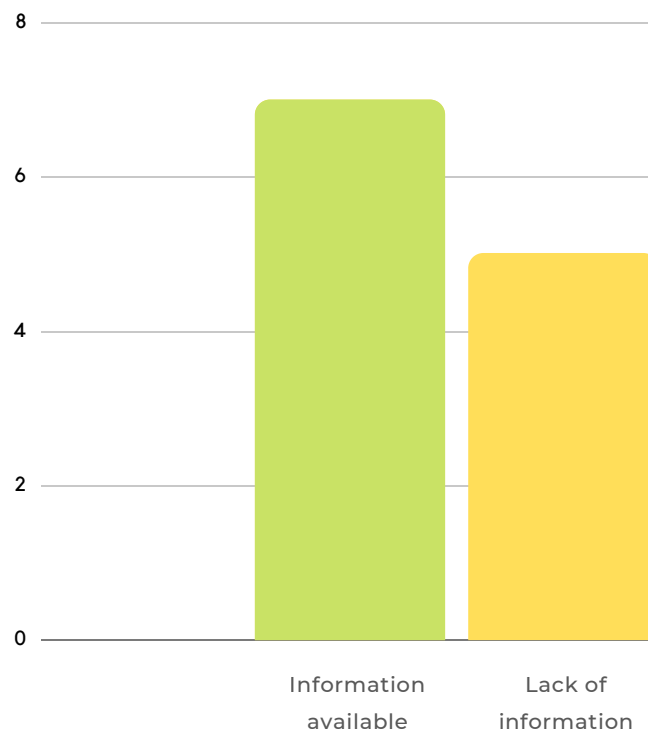
Where vaccinations were not yet being offered, little information was available nationally or from patients' local health services. There was a shared concern that some people may be making decisions on vaccination based on assumptions, rumours, or unreliable sources.

In Germany and Spain, participants had noticed that the information being provided internationally, nationally, and by individual doctors sometimes differed. One participant reported feeling overwhelmed by the constant stream of new information on COVID-19 and vaccines.

“In Germany, everybody who gets a vaccination has to have an educational interview with the doctors before they get it.” Patient 5



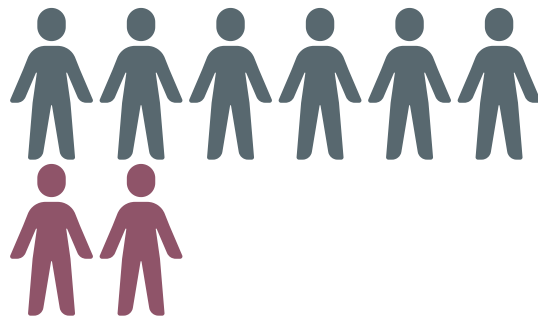
AVAILABILITY OF INFORMATION ON
COVID-19 VACCINATION
(ACCORDING TO 12 PATIENTS AND CAREGIVERS
WHO SHARED THEIR EXPERIENCE)



CONFIDENCE IN COVID-19 VACCINES

Participants shared positive views about the COVID-19 vaccine. They felt that the benefits were high for patients with myeloma or AL amyloidosis due to their increased disease risk.

Six participants felt confident about having the vaccine, with two specifically stating their confidence in the science and regulatory approval process. In contrast, two participants shared concerns over the risk of blood clots or low platelet counts with the AstraZeneca vaccine.



6 out of 8 Patients felt confident about receiving COVID-19 vaccinations

“

“No concerns [about the vaccine] at all because I trust science and research.”

Patient 9

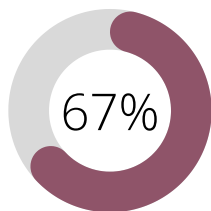
Gaps in knowledge about vaccine efficacy were also discussed. In two focus groups, there was a discussion about whether the vaccines worked well in patients with blood cancers. Some participants had seen a recent news article that reported low effectiveness in people with blood cancers, which was causing concern.

Some participants were aware that people taking medications for myeloma may need to pause these before and after vaccination. Three participants felt there was a lack of certainty over how long this window of time should be.

HOW HAVE THE COVID-19 PANDEMIC AND RESTRICTIONS AFFECTED PATIENTS AND CAREGIVERS EMOTIONALLY AND PSYCHOLOGICALLY?

PSYCHOLOGICAL IMPACT

The psychological impact of the pandemic and related measures varied. When asked how they felt during the COVID-19 pandemic, 10 patients and caregivers said restrictions had affected their lives negatively. These participants described how social distancing led to feelings of loneliness, anxiety, stress, boredom, missing friends and family, or missing physical connection. Two participants described some of the pressures of living during the pandemic as ‘almost unbearable’ or ‘stressful and exhausting’.



of patients and caregivers said restrictions due to COVID-19 negatively affected their lives

The threat of increased risks from COVID-19 was a source of tension, stress, and anxiety for some participants, especially when they needed to visit a hospital.

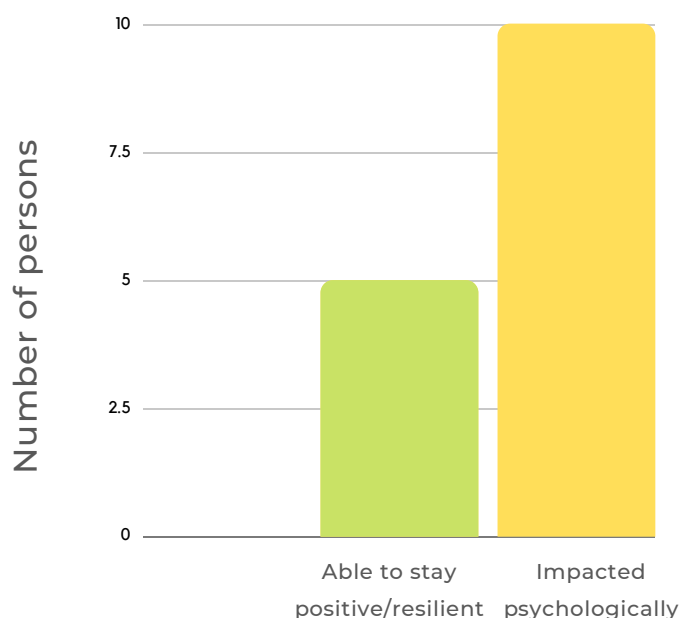


“The longer-term effect was that the impact was quite severe and [meant] not being able to get close to my grandchildren, for example. And normally we would see each other every few months.” Patient 10



“At the beginning, when I had to go to the hospital, I had a feeling of stress and exhaustion when I got home and having to change quickly and take a shower right away... It seems that now we have got used to doing all this and it is easier to cope with.” Patient 7

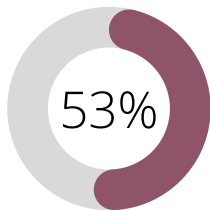
PSYCHOLOGICAL IMPACT OF THE COVID-19 PANDEMIC (OF 15 PATIENTS AND CAREGIVERS WHO SHARED THEIR FEELINGS)



Nine patients said that living with myeloma or AL amyloidosis heightened the challenges of the COVID-19 pandemic and restrictions. For example:

- Three patients found the need to socially distance more strictly than the general public was an added pressure in their lives
- One patient said delays in myeloma treatment due to the pandemic measures were a source of great psychological burden for the patient population in general
- One found receiving news of their advancing AL amyloidosis tough coupled with the COVID-19 pandemic and related measures

“I was staying away from everyone... so, the psychological impact, I think apart from being a blood cancer patient, which is a higher impact than for the normal population.” Patient 10

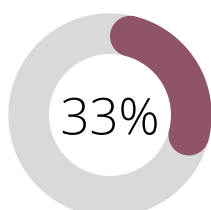


of patients experienced additional challenges from the COVID-19 pandemic and restrictions due to living with myeloma or AL amyloidosis

“Last August my haematologist told me that there was no treatment for my disease [myeloma] and that I should be ready to die. [After] a private consultation, I was told that it was not too serious and that it could be treated... the truth is that it has been quite tough, coupled with the pandemic situation.” Patient 13

RESILIENCE

Five participants felt they were able to cope with the challenges of the pandemic, describing a feeling of resilience. A few mentioned that isolation measures during their myeloma treatment (e.g. a transplant) made them feel more prepared for facing lockdown.



of patients and caregivers felt they were able to cope with the challenges of the COVID-19 pandemic and restrictions related to it



“

“We have some resilience capability. That’s incredible. We had to adapt.” Patient 8

Two patients who felt resilient during the pandemic explained that surviving myeloma was still their primary focus.

“

“The pandemic has not affected me emotionally. My concern is to overcome the disease [myeloma], to get it into remission, to be free of pain.” Patient 9

IMPACT ON ACTIVITIES

Activities that people said they had to stop during the COVID-19 pandemic included going on holiday, meeting friends, having visitors, dancing, outdoor exercise (walking or jogging), and indoor exercise (swimming or using the gym). Five participants mentioned they missed not only the activity itself but also the social opportunity it provided.

One participant said their usual hobbies and interests were not affected by the pandemic.

“It had a great impact on my life. I had a regular table with friends every two weeks. And what my husband and I do is dancing tango regularly. But it was all cancelled.” Patient 5

SUPPORT FROM FRIENDS AND FAMILY

Not many participants commented specifically on the support provided by friends and family during the COVID-19 pandemic. However, the three who did all shared that their friends and family respected their need to be especially cautious and supported them in reducing the risks of being infected with the coronavirus.

“So for about a year, nobody, no stranger came into our house ... to protect me, because I am at high risk. And we knew that this was the situation and everybody needed to respect it... That was tough.” Patient 6

A caregiver, who supports a patient living in a separate home, spoke of how being single and living alone made the COVID-19 pandemic and restrictions extremely difficult to live through.

“So this fear [of transmitting COVID-19] kept me mainly indoors. And this, I want to tell you as a single person, sometimes it’s almost unbearable. Thank God I am fully computer literate. Thank God I kept my sanity...I read a lot and I watched a lot. But still, I miss my life.” Caregiver 1

LIFE BALANCE

We asked participants whether they had been able to maintain a balance in their lives during the COVID-19 pandemic. Of the five who responded, all felt they had achieved a balance.

RECEIVING A COVID-19 DIAGNOSIS

One participant was diagnosed with COVID-19 during the pandemic. Two others had family members who were diagnosed. The impact of COVID-19 diagnosis differed among these three participants, with feelings ranging from scared, to determined, to fearless.

“

“I was the first in my family to be diagnosed [with COVID-19]. At first, I was afraid for my parents... I was very, very scared for them, but thank God, they didn’t catch it.” Patient 7

“

“In January my wife tested positive with COVID[-19]. This was a massive blow to the household... and it was very, very hard because we don’t have a very big house. What we did is we instituted extremely high protocols in the house, including only one person in any room at any time. We were lucky in a way that I did not get it. But it was the hardest time.” Patient 1



WHAT SUPPORT HAS HELPED PEOPLE COPE DURING THE COVID-19 PANDEMIC AND RESTRICTIONS?

We asked participants to share the sources of support that they (or others) had found useful during the COVID-19 pandemic. In general, the answers focused on support specific to people living with myeloma and AL amyloidosis.

“*The internet, as a network, is one of the most helpful things in the pandemic. I have seen a lot of webinars.*” Patient 5

In one of our focus groups, participants shared concerns about the support available for people who are not typically online. It was felt that these people may be unaware of the support available to them and how to access it. As many services have moved online during the COVID-19 pandemic, these people may be more isolated than previously.

“*I also connect to [an online social group] – because I feel very accompanied, and I receive a lot of support. Due to the pandemic, the association has moved from the small room it used to have in the haematology ward to the digital world.*” Patient 9

PARTICIPANT-REPORTED SOURCES OF INFORMATION AND SUPPORT DURING THE COVID-19 PANDEMIC

INFORMATION	SUPPORT
Cancer charities and foundations (websites and telephone service)	Hospital-run support groups
Online conferences and education	Support groups run on social media and the internet
Internet searches	Self-help books
Media (news)	
Advice provided by the National Health Service	
Online literature library (PubMed)	
Information from doctors and specialists	



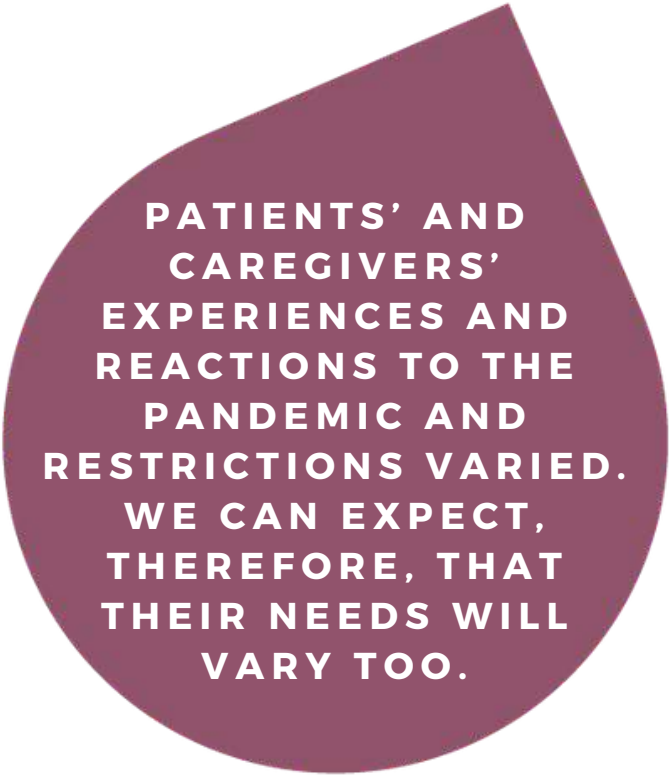
“We had more access to doctors and information. Haematologists gave us [the opportunity] almost every 2 weeks to have a meeting with someone talking about COVID-19 and myeloma; to learn what is good and what is bad and what is true and what is wrong.” Patient 6

CONCLUSIONS AND RECOMMENDATIONS

Our focus group participants painted a picture of how people with myeloma and AL amyloidosis and their caregivers in multiple countries have been impacted by the COVID-19 pandemic and the restrictions related to it. Some of their experiences and challenges are in common with those of the general population. However, living with myeloma and AL amyloidosis during this crisis brought extra challenges and psychological strains in a variety of ways. Crucially, for some patients, treatment for myeloma, AL amyloidosis, and their complications was delayed.

Their experiences during the COVID-19 pandemic and restrictions underscored patients' and caregivers' needs for human connection, support, and clear information. Patients' and caregivers' experiences and reactions to the pandemic and restrictions varied. We can expect, therefore, that their needs will vary too.

Our focus groups identified that efforts to control COVID-19 differed by country, region, and hospital. During the pandemic, access to healthcare and COVID-19 vaccinations has not been consistent across countries. Information provision has also varied widely.



**PATIENTS' AND
CAREGIVERS'
EXPERIENCES AND
REACTIONS TO THE
PANDEMIC AND
RESTRICTIONS VARIED.
WE CAN EXPECT,
THEREFORE, THAT
THEIR NEEDS WILL
VARY TOO.**



Learning from these focus groups, MPE and member organisations can support patients with myeloma and AL amyloidosis by:

- Working with governments to ensure priority access to COVID-19 vaccines for patients with myeloma and AL amyloidosis as well as their caregivers and household members (where governments have not already made this commitment).
- Collecting and sharing information on COVID-19 and vaccination that is easy to understand, accurate, up to date, and answers patients' and caregivers' questions.
- Ensuring continuity of support networks for patients and caregivers through regular communication, virtual support groups and educational webinars, email, and social media.

Ensuring that patients who are not frequently online are aware of the

- support available to them and have ways to connect and access support, including the use of non-digital communication, access to technology, and training to improve computer literacy skills.

- Asking healthcare professionals to provide patients and their families with information on local and national support groups, patient information, and peer-to-peer patient and family services.
- Continuing to measure the long-term impact of COVID-19 on patients and caregivers (such as delays in diagnosis and treatment), and taking appropriate actions.
- Continuing to advocate for patient preferences regarding the way that treatment and care is delivered during the pandemic, for instance considering the use of telemedicine and reduced clinic visits.

ACKNOWLEDGEMENTS

We wholeheartedly thank the patients and caregivers who took part in these focus groups. We are grateful for their time and generosity in sharing their unique experiences and insights. Their openness has allowed us to better understand the impact of the COVID-19 pandemic and restrictions, which can be used to address the needs of people living with myeloma and AL amyloidosis and their caregivers.

The analysis of the focus group transcripts and the development of this report were supported by Excerpta Medica – EMPowering Patients.



Ten years together.

CONTACT US



Myeloma Patients Europe AISBL
Avenue Louise 149/24
1050 Brussels - Belgium



info@mpeurope.org



www.mpeurope.org



[@mpeurope](https://www.facebook.com/mpeurope)



[@MyelomaEurope](https://twitter.com/MyelomaEurope)



[Myeloma Patients Europe](https://www.linkedin.com/company/myeloma-patients-europe)



[Myeloma Patients Europe](https://www.youtube.com/channel/UC...)