



REPORT

MPE
Myeloma
Patients
Europe

10TH
ANNIVERSARY
SINCE 2011

Ten years together.

Assessment of the needs of patient organisations during the COVID-19 pandemic, April 2021

HIGHLIGHT REPORT FROM THE
SECOND SURVEY OF MPE'S MEMBER
ORGANISATIONS



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Europe and Excerpta Médica.
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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 myeloma and AL amyloidosis patients, as well as their caregivers, every day.

As the SARS-CoV-2 (COVID-19) pandemic unfolded in 2020, we became aware that the pandemic, as well as the restrictions imposed, were impacting the healthcare and lives of people with myeloma and AL amyloidosis, and their caregivers in multiple ways. The crisis also brought unique challenges to our member organisations in connecting with and supporting their patient communities.

To understand how we could best help, MPE conducted research to learn more about the impact of the pandemic and lockdown measures, and the needs of patients, carers and member organisations. A survey of 34 members in April 2020 revealed a significant emotional and psychosocial impact, as well as treatment delays and problems accessing wider healthcare and support services in some countries. Although members were adapting, some had concerns over their financial resilience and future organisational sustainability.

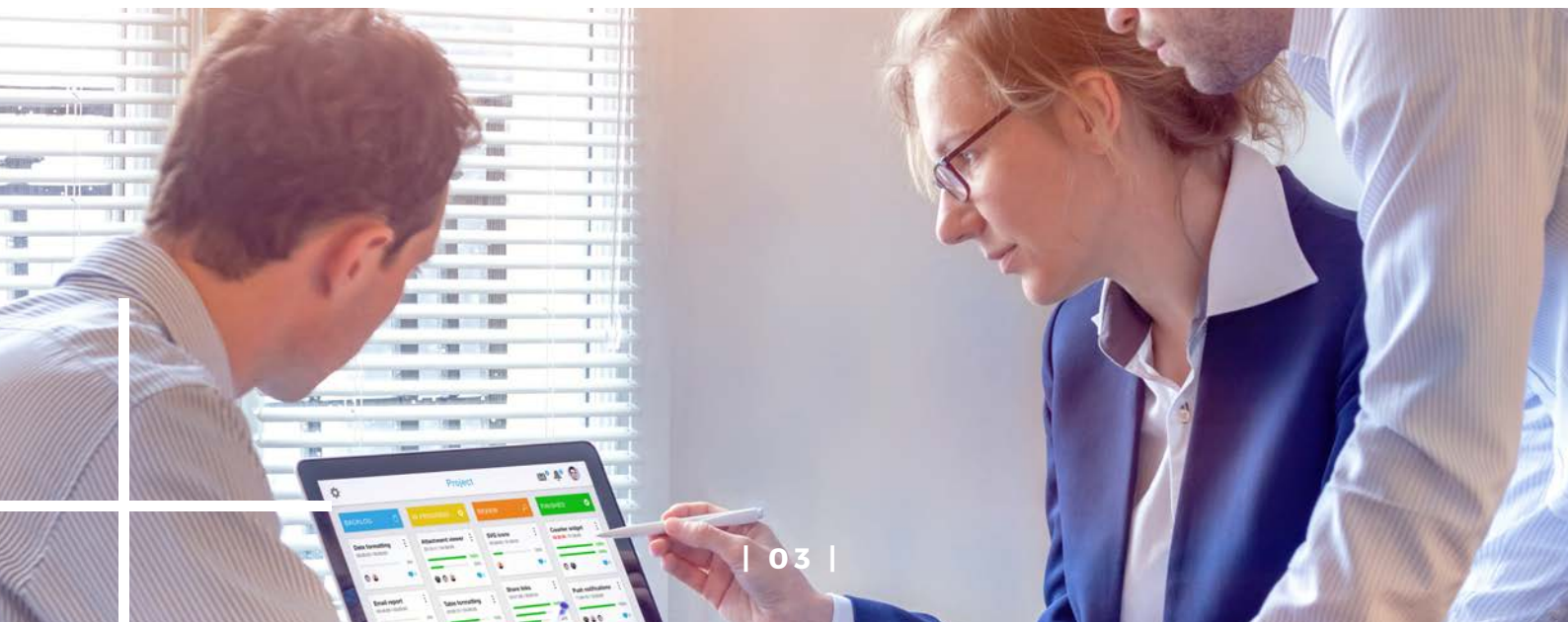
In response, and as part of our COVID-19 Outreach Workstream, MPE developed a range of educational materials and publications in 15 languages, a series of informational videos, and a microsite housing general, local and national information. In April 2021, we conducted a second survey of member organisations to assess how their needs in relation to the COVID-19 pandemic and lockdown measures had evolved. This report summarises the results.

METHODS

This survey was conducted through informal, structured interviews with representatives from member organisations who wished to participate over the course of four weeks. In total, 28 member organisations participated across 25 countries.¹ In cases where there was more than one respondent per country, they are labelled as Romania 1 and Romania 2, for example.

The questions used in the survey are shown in Appendix 1.

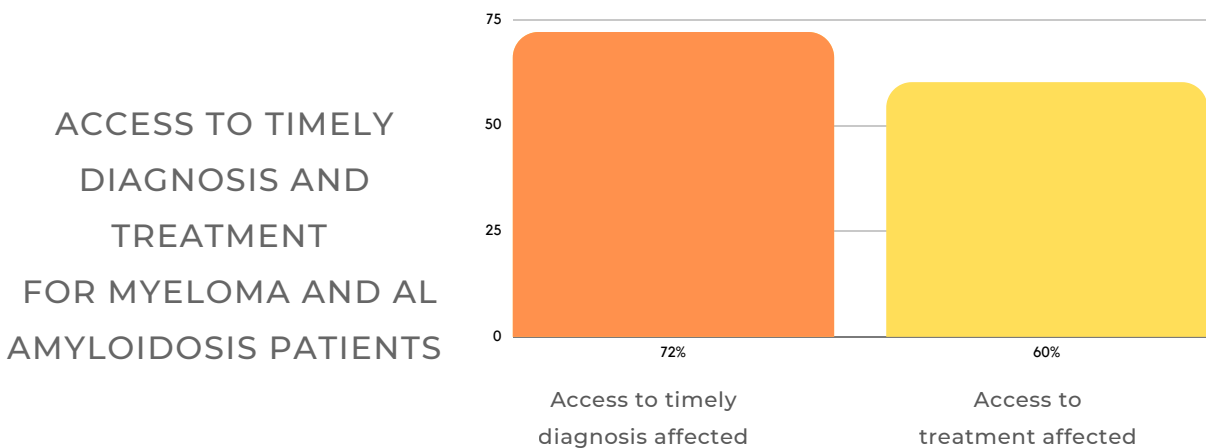
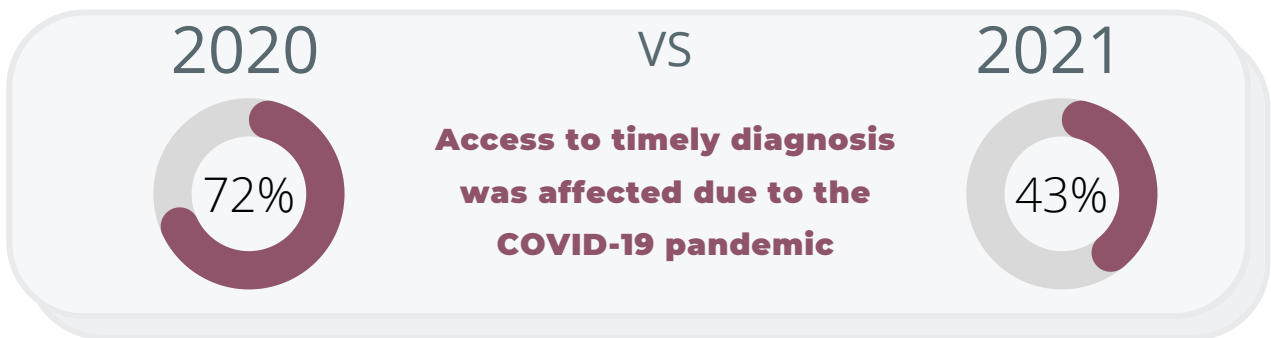
Armenia (1), Austria (1), Czech Republic (1), Denmark (1), Finland (1), France (1), Germany (2), Iceland (1), Israel (2), Latvia (1), Lithuania (1), Macedonia (1), Malta (1), Norway (1), Poland (1), Portugal (1), Romania (2), Russia (1), Serbia (1), Slovenia (1), Spain (1), Sweden (1), The Netherlands (1), Turkey (1), UK (1).



HOW DID THE COVID-19 PANDEMIC AND LOCKDOWN MEASURES AFFECT PATIENTS WITH MYELOMA AND AL AMYLOIDOSIS AND CARERS IN MPE MEMBER COUNTRIES?

ACCESS TO DIAGNOSIS AND TREATMENT

Access to timely diagnosis of myeloma and AL amyloidosis was affected in 18 of 25 countries (72%). Access to treatment for myeloma and AL amyloidosis was affected in 15 countries (60%). This is an increase over our 2020 survey, in which 43% of participants said treatment was affected



Reported in:

Czech Republic, Finland, Germany, Israel, Latvia, Macedonia, Malta, Poland, Portugal, Romania, Russia, Serbia, Slovenia, Spain, Sweden, The Netherlands, Turkey, UK

Armenia, Czech Republic, Finland, France, Israel, Latvia, Macedonia, Poland, Romania, Russia, Serbia, Spain, Sweden, Turkey, UK

Four out of 28 MPE member organisations saw a reduction in the number of newly diagnosed patients contacting their organisation for information or support. They felt this might signal a reduction in the number of new diagnoses due to problems accessing medical care or specialists, or fear of visiting a hospital due to the increased risk of contracting COVID-19.

Some respondents, however, felt that in comparison to the beginning of the pandemic, the impacts on diagnosis and treatment had reduced over time.

- *“Patients have to be tested at the same hospital they get treatment from, which is creating additional barriers and burdens for patients.”* Poland
- *“Maybe some stem cell transplants were postponed but not regular treatment.”* The Netherlands
- *“There has been some delay in treatment, especially at the beginning, because patients were scared and didn't go to their doctor's appointment.”* Finland
- *“In smaller cities, where services are overloaded and there is less access to doctors, [patients saw delays].”* Portugal
- *“There are more challenges for patients to safely access treatment they were receiving before COVID.”* Denmark
- *“Might not be getting chemo since it requires hospitalisation, so they can get oral treatments.”* Sweden
- *“Approximately 95% of drugs are not registered in Armenia, patients try to get these from other countries (e.g., India or Russia); this is very hard during the pandemic.”* Armenia

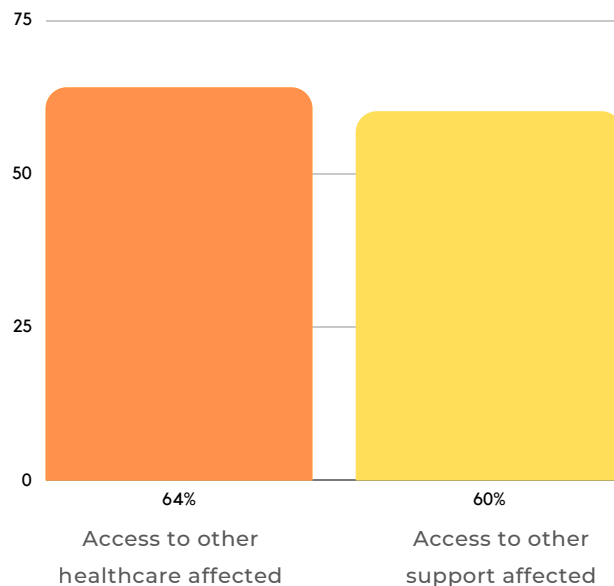
**RESPONDENTS
REPORTED A
VARIETY OF
BARRIERS TO
ACCESSING
TREATMENT,
INCLUDING:**

ACCESS TO DIAGNOSIS AND TREATMENT

Participating members reported that access for myeloma and AL amyloidosis patients to other healthcare services was affected in 16 of 25 countries (64%). Access to other support services, such as counselling, was affected in 15 countries (60%).

These results suggest an increase in the difficulty of obtaining other services, compared with our first survey (in which 48% of participants said other healthcare services were affected and 30% said support services were affected).

ACCESS TO WIDER HEALTHCARE AND SUPPORT



Reported in:

Austria, Czech Republic, Denmark, France, Latvia, Macedonia, Norway, Poland, Portugal, Romania, Serbia, Slovenia, Spain, Sweden, Turkey, UK

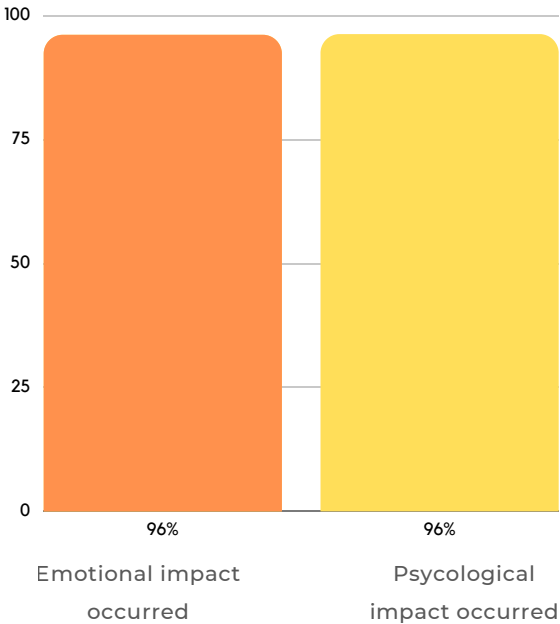
Austria, Czech Republic, Denmark, France, Latvia, Macedonia, Malta, Poland, Romania, Serbia, Slovenia, Spain, Sweden, Turkey, UK



EMOTIONAL AND PSYCHOLOGICAL IMPACT

Nearly all participating members reported an emotional and psychological impact on patients with myeloma or AL amyloidosis and their carers (24 of 25 countries; 96%). These results are similar to last year.

EMOTIONAL AND PSYCHOLOGICAL IMPACT OF THE PANDEMIC AND LOCKDOWN MEASURES



Reported in:

Armenia, Austria, Czech Republic, Denmark, Finland, France, Germany, Iceland, Israel, Latvia, Lithuania, Macedonia, Malta, Norway, Poland, Portugal, Romania, Russia, Serbia, Slovenia, Spain, Sweden, Turkey, UK

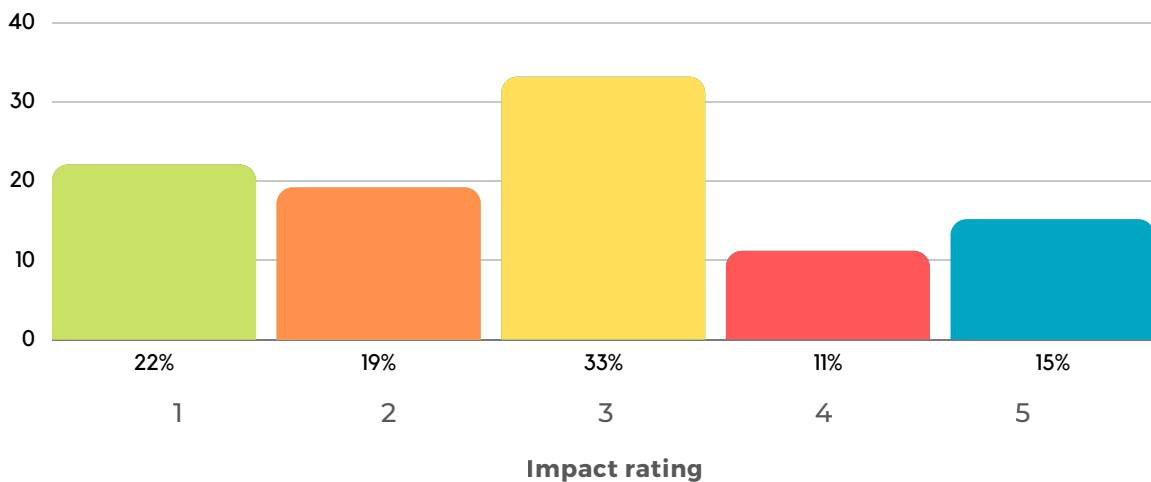
Armenia, Austria, Czech Republic, Denmark, Finland, France, Germany, Iceland, Israel, Latvia, Lithuania, Macedonia, Malta, Norway, Poland, Portugal, Romania, Russia, Serbia, Slovenia, Spain, Sweden, Turkey, UK

Three respondents reported that psychological services and support meetings for patients had been cancelled, postponed, or moved to virtual (online) delivery. They felt that virtual support was not as effective as face-to-face support. Two respondents mentioned that older patients had difficulty accessing virtual support.

SCALE OF THE IMPACT ON TREATMENT

We asked members to rate how much the COVID-19 pandemic and lockdown measures have affected access to treatment for myeloma and AL amyloidosis. Respondents were asked to rate treatment impacts on a scale of 1 to 5, where 1 was no impact and 5 was significant impact. A third of members ranked the impact 3 out of 5 ('some impact'), while other members saw a smaller or greater impact.

IMPACT OF COVID-19 AND LOCKDOWN ON TREATMENT FOR MYELOMA AND AL AMYLOIDOSIS



No impact

Iceland, Germany 2, Norway, Poland, Slovenia, The Netherlands

Some impact

Israel 1 and 2, Czech Republic, Denmark, France

Armenia, Austria, Finland, Germany 1, Latvia, Lithuania, Malta, Romania 1, UK

Significant impact

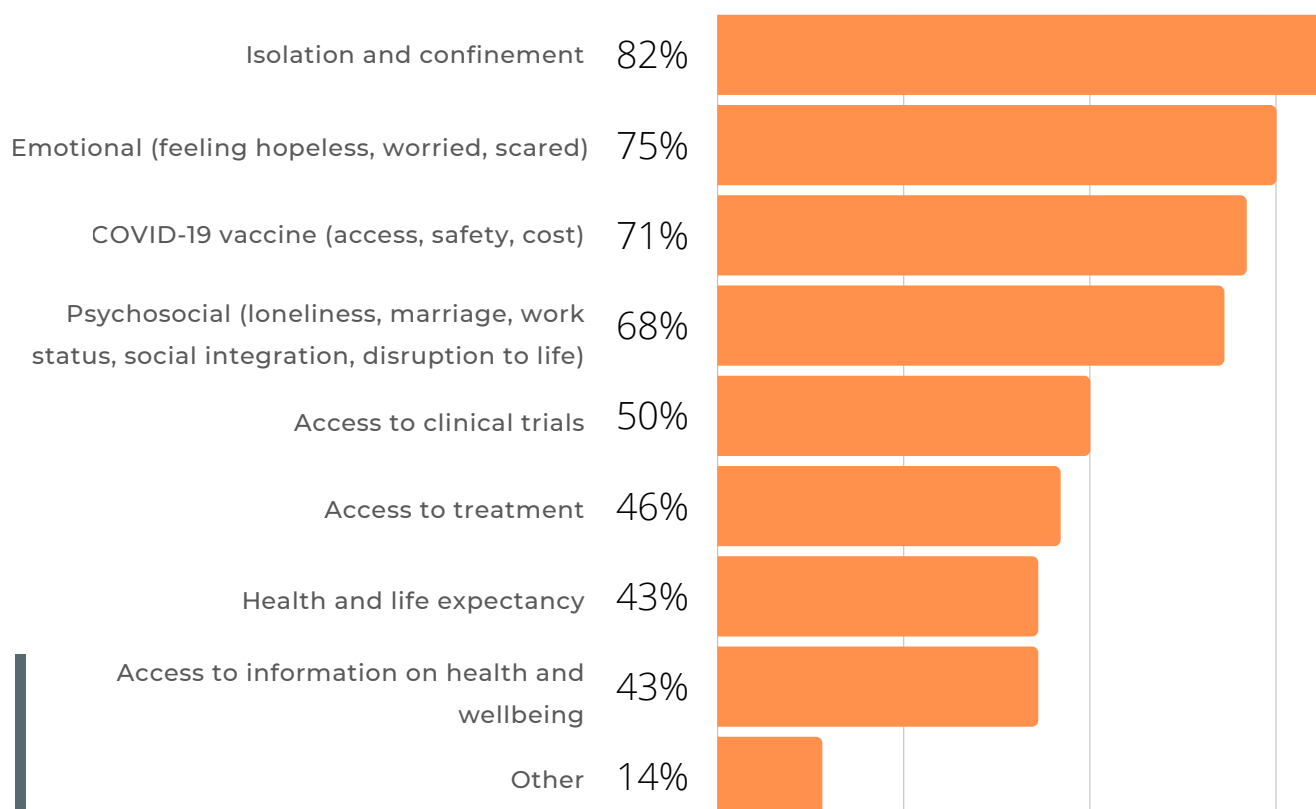
Romania 2, Spain, Sweden, Turkey

In their comments, three members mentioned that they felt the impact was greater at the start of the pandemic, but had since reduced. Treatment delays, including stem cell transplants, were also mentioned.

CONCERNS OF PATIENTS AND CARERS

Eleven of 28 respondents (39%) told us they knew patients and carers who had specific concerns regarding the COVID-19 pandemic and lockdown measures. Six of 28 respondents (21%) said they personally had specific concerns for patients and carers. The most commonly reported concerns were about the COVID-19 vaccine, isolation and confinement, emotional impact, and psychosocial impact. These concerns were broadly similar to those reported in our last survey (we did not ask previously about concerns related to the COVID-19 vaccine).

CONCERNS OF (OR FOR) PATIENTS AND CARERS



- *“Isolation and confinement have got worse with the length of the pandemic...there have been concerns around vaccine safety due to J&J and AZ.” Austria*
- *“The psychosocial impact for those living alone has been significant. They have been reaching out more for support.” Denmark*
- *“We have good access to vaccines at no cost. We are more concerned about how effective the vaccine is for myeloma patients.” Iceland*
- *“Will the vaccine be harmful? Will it help amyloidosis patients with impaired immune systems?” Israel 2*
- *“We have noticed that the number of requests to see our psychologists has increased in the last year.” Lithuania*
- *“Above all, they are scared of not receiving the treatment they need, also isolation and emotional impact of COVID.” Spain*
- *“Patients cannot choose which vaccine they get so they are worried.” Turkey*

**COMMENTS
FROM MEMBER
ORGANISATIONS
INCLUDED:**

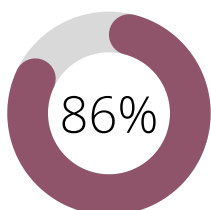
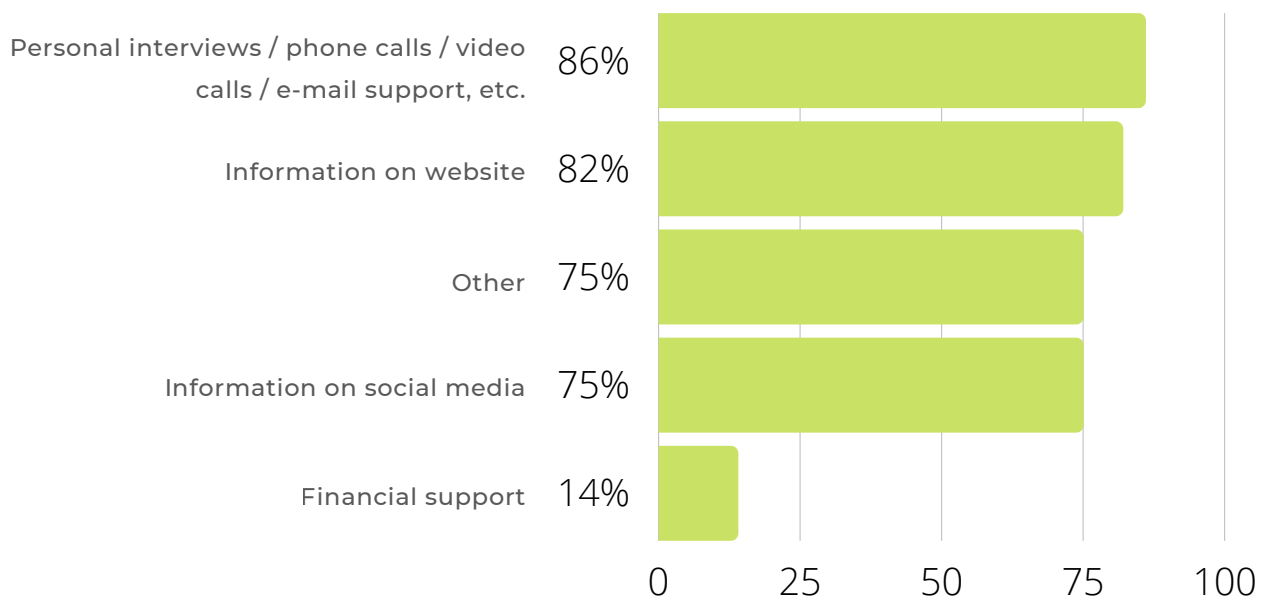


WHAT INFORMATION AND SUPPORT ARE AVAILABLE TO PATIENTS AND CARERS

INFORMATION PROVIDED BY MEMBER ORGANISATIONS

All 28 respondents (100%) told us that their organisation was providing information and support to their members via their website, social media, and/or through personal interactions (for example, phone calls, video calls, and e-mail). Only 4 of 28 organisations (14%) were providing financial support to their members.

INFORMATION AND SUPPORT PROVIDED TO PATIENTS AND CARERS



Most MPE member organisations provided support through phone and video calls, personal interviews or email



Under 'other,' 11 organisations mentioned webinars or online meetings (often about COVID-19), which in comparison to our last survey, seem to be utilized more often. Frequently, healthcare professionals were involved in webinars. Other ways of providing information and support included an information hotline, magazine, newsletter, printed information, WhatsApp group, legal support, taxi services, and a website for consulting healthcare professionals.

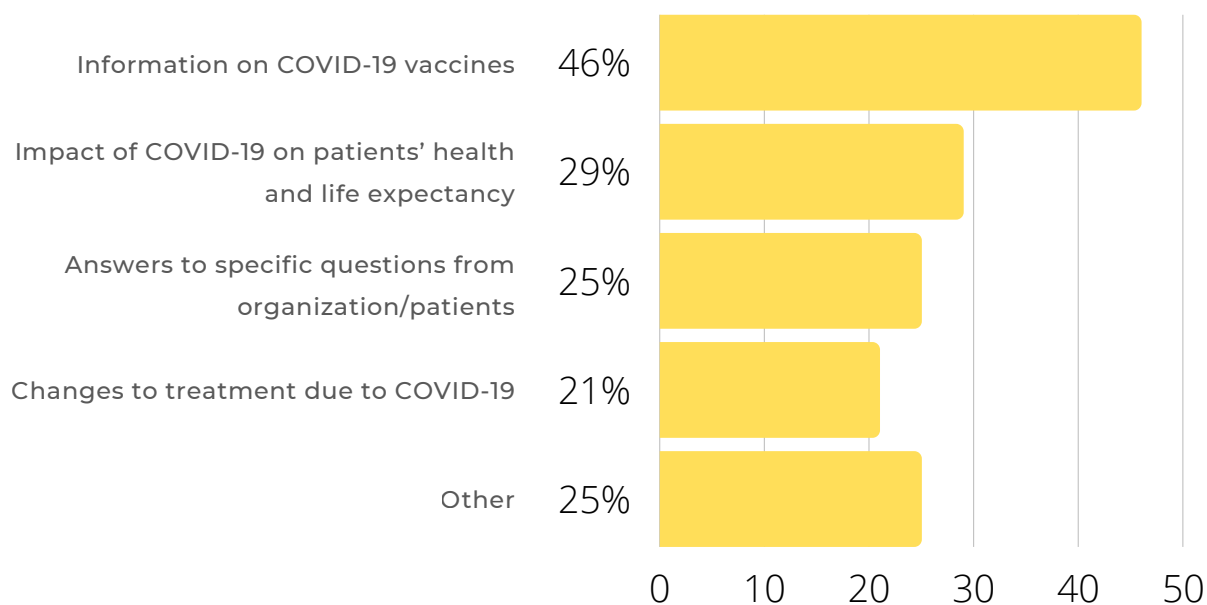
TRANSLATION OF MPE CONTENT FOR MEMBER ORGANISATIONS

As part of our COVID-19 Outreach Workstream, MPE has been translating educational resources, infographics, and news stories into members' native languages. We have also provided templates where translated information can be adapted, branded, and disseminated by local organisations to patients and carers.

In our first survey, 50% of member organisations said they would like to receive translated materials. In the current survey, this rose to 61% (17 of 28 respondents).

Help with translations was requested on the following topics:

MATERIALS THAT ORGANISATIONS WOULD LIKE TRANSLATED BY MPE



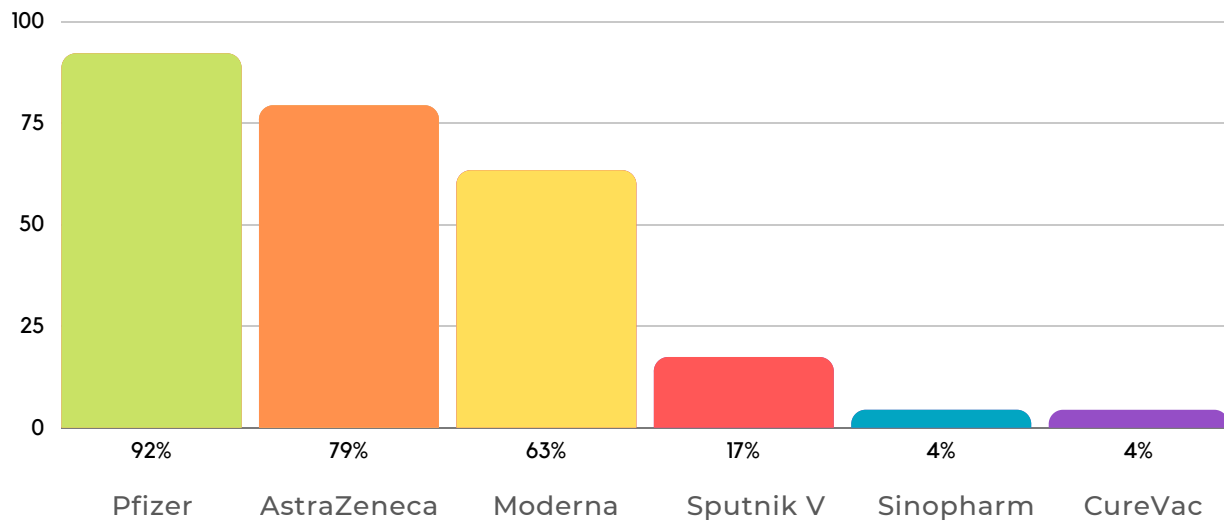
Under 'other', respondents mentioned information on treatment, myeloma, clinical trials, nutrition, physical activity, patients' rights, infographics, and congress reports.

CAN PATIENTS AND CARERS ACCESS COVID-19 VACCINES?

ACCESS AT A COUNTRY LEVEL

In 23 of 25 countries (92%), COVID-19 vaccines were available at the time of the survey. The vaccines available differed by country. Most countries used multiple vaccines – most commonly from Pfizer, AstraZeneca, and Moderna.

VACCINE BRANDS AVAILABLE



A number of respondents reported that use of the AstraZeneca vaccine was under review at the time of our survey.

ACCESS TO VACCINATION FOR PATIENTS AND CARERS

While COVID-19 vaccines were available at a national level in most countries, in some countries not all patients were able to receive the vaccine at the time of our survey. In 20 of 28 countries (73%), patients with myeloma and AL amyloidosis were being prioritised for vaccination.

COST OF THE VACCINE

In all 28 countries, the vaccine was provided free of charge.

WILLINGNESS TO BE VACCINATED

Twenty-six out of 28 respondents (93%) felt that patients with myeloma and AL amyloidosis were willing to get vaccinated. However, despite the high rates of willingness reported, 12 organisations (43%) also stated that patients do have concerns over the vaccine's safety, efficacy, and potential impacts on their myeloma or AL amyloidosis treatment.

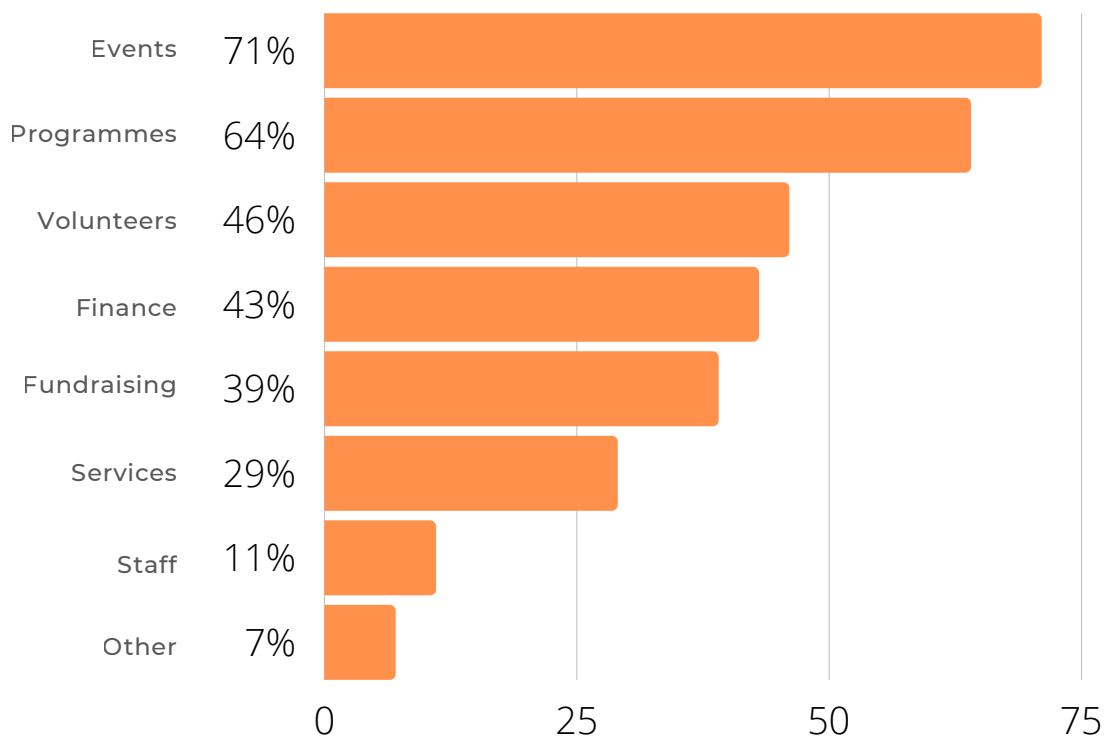
WHAT IS THE IMPACT OF THE COVID-19 PANDEMIC AND LOCKDOWN MEASURES ON MEMBER ORGANISATIONS?

SPECIFIC IMPACT ON MEMBER ORGANISATIONS

Most member organisations reported that their programmes and events were impacted by the pandemic. Over a third also reported financial, volunteering, and fundraising concerns.

Compared with our last survey, the proportion of organisations reporting concerns regarding volunteers has risen sharply (from 9% to 46%).

IMPACT ON MEMBER ORGANISATIONS



A number of organisations explained how they had adapted during the pandemic. For example, organisations commonly reported that face-to-face events were changed to virtual (online) meetings. However, other challenges were harder to overcome.

- *“Events...all face-to-face cancelled, but webinars have been extremely successful. 500x better participation which has been a great experience.”* UK
- *“We have around 160 volunteers that usually help with the organisation of info days or events and at this moment they can do nothing.”* The Netherlands
- *“Having all of the administrative and operational requirements in place for local organisations has been tough.”* Sweden
- *“We have less sponsorships because online activities are cheaper so companies have reduced their grants.”* Spain
- *“At this moment, we don’t have any volunteers; all of them disappeared...the only regular sponsorships we receive are for the maintenance of the website and phone calls. The rest were event-related and right now we don’t have any events or activities, so we don’t have a budget.”* Romania 1
- *“Big impact on fundraising and events...we usually have concerts and dinners.”* Portugal
- *“Pharmaceutical funding has been affected as the focus has all shifted to COVID rather than other disease areas – therefore there has been less budget available and made available to patient organisations.”* Macedonia



**COMMENTS
FROM MEMBER
ORGANISATIONS
INCLUDED:**

CONCERNS FOR THE FUTURE

11 of 28 organisations (39%) had concerns about the future, which is a decrease from the last survey (53%). Concerns included the sustainability of the organisation's volunteer base, securing financial support, and maintaining patient engagement and membership. Some respondents said they were concerned that their volunteer base had shrunk or that volunteers were exhausted due to changed ways of working.

WHAT SUPPORT ARE MPE MEMBER ORGANISATIONS RECEIVING TO CONTINUE THEIR WORK?

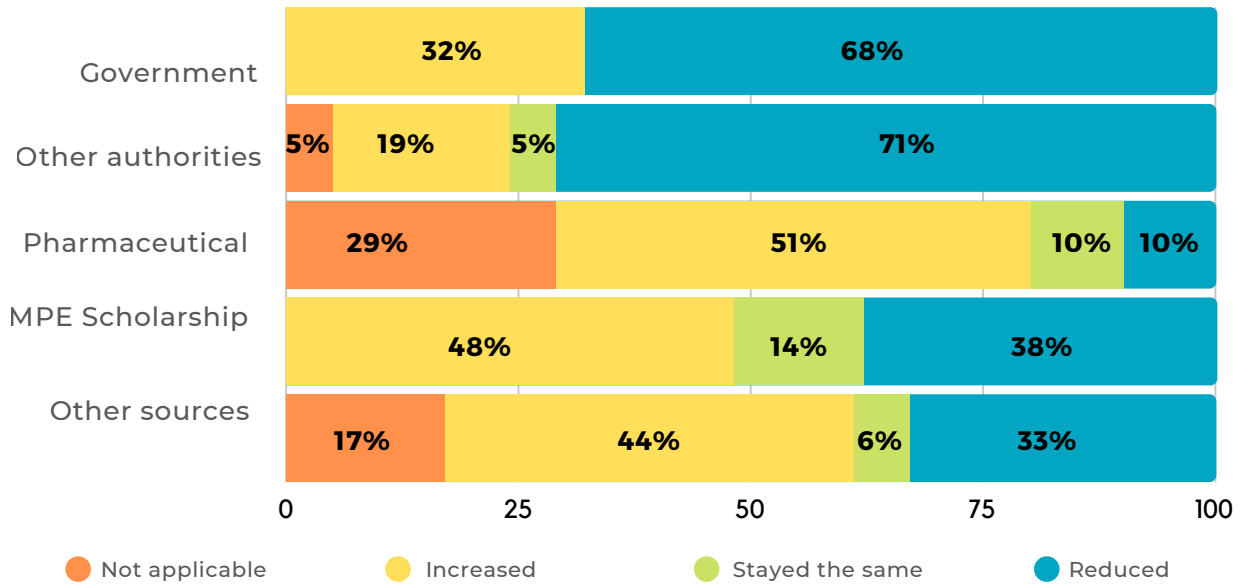
EXTERNAL FUNDING

The most common sources of financial support for the member organisations participating in our survey were pharmaceutical (23 of 28 organisations; 82%) or an MPE Scholarship (13 of 28 organisations; 46%). Fewer than half of the organisations received support from government or other authorities.

Of the 23 organisations who receive pharmaceutical support, 8 had seen a reduction in funding, 2 had seen an increase, and the others saw no change. Thirteen of 23 organisations identified the MPE scholarship as a source of funding.



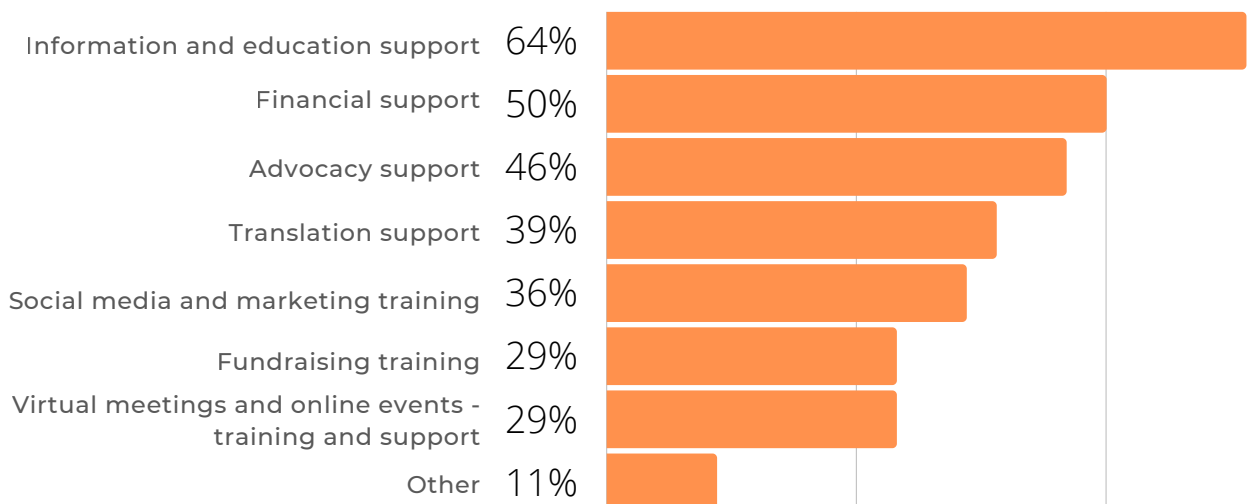
CHANGES IN FUNDING (BY SOURCE)



REQUESTED SUPPORT FROM MPE

Member organisation requests for support was quite varied and depended on the challenges that the organisation faced. Eighteen of 28 (64%) member organisations said they would like information and educational support from MPE. About half would like translation, financial, or advocacy support.

HOW MPE CAN HELP MEMBERS





USE OF MPE COMMUNICATION CHANNELS

Nineteen of 28 respondents (68%) said that the MPE website was useful and 17 of 28 (61%) said that MPE's social media channels were helpful for their organisation and their patient community. Seven organisations (25%) said the MPE Telegram Channel was useful.

Feedback included:

- *"MPE is a reference. When you need some information, you go to MPE because you know you can find what you need there. It is also accessible from the user perspective."* Portugal
- *"The website is very useful because of the resources it contains."* Armenia
- *"Our members aren't using the MPE channels because we are not actively promoting these for our patients/members. But this will likely change in the future."* Denmark
- *"For me, the MPE website and the MPE social media channels are useful. Also, newsletters are very useful to learn more about MPE projects and activities."* Lithuania
- *"Website is not mobile-device friendly – makes access very difficult. Typically use more Facebook as it is very user friendly."* Germany 1
- *"We share a lot of MPE's posts – especially Facebook, these are shared on our Facebook page with a translation."* Macedonia

SUMMARY OF KEY FINDINGS

IMPACTS ON PATIENTS AND CARERS

- In about two-thirds of countries surveyed, the COVID-19 pandemic and lockdown measures have affected access to timely diagnosis and treatment for myeloma and AL amyloidosis as well as wider healthcare and support services.
- The COVID-19 pandemic and lockdown measures continue to affect patients and carers both psychologically and emotionally. This is also reflected in the type of information and support that organisations are providing to their members, including increased counselling services and psychosocial support.
- Common concerns of patients and carers (and patient organisations) centre on COVID-19 vaccination, isolation and confinement, emotional impact, and psychosocial impact.
- COVID-19 vaccination programmes had begun in nearly all countries surveyed and the majority of countries prioritized the vaccination of patients with myeloma and AL amyloidosis.

IMPACT ON MEMBER ORGANISATIONS

- Member organisations continue to be impacted by the COVID-19 pandemic and lockdown measures, with many organisations reporting changes to events, programmes, finances, and volunteers. These themes were often a source of concern for the future.
- Some organisations have successfully adapted to provide services during the COVID-19 pandemic. For others, challenges such as funding reductions were an ongoing problem.

- This survey highlights the importance of MPE scholarships, which were awarded to 17 organisations during 2020, especially in light of reductions in pharmaceutical support experienced by some members.
- Members most frequently wanted help with information and education, translation, funding, and advocacy.

CONCLUSIONS

This second survey of member organisations, conducted in April 2021, reveals that the COVID-19 pandemic and lockdown measures continue to impact patients with myeloma and AL amyloidosis, carers, and patient organisations. While there are some common themes, impacts also differ by country and member organisation.

The findings of this survey signal an ongoing need for the MPE COVID-19 Outreach Workstream. They underline the importance of MPE providing varied and timely solutions that meet the differing needs of member organisations. Furthermore, the survey strengthens the recommendations made in our recent focus group report on COVID-19 impacts.



MPE COVID-19 OUTREACH WORKSTREAM - NEXT STEPS

While the effects of COVID-19 on our members and their patient communities persist, MPE recognizes that we must continue to support organisations as their needs evolve and look toward mitigating the long-term impacts of the pandemic. Based on the findings of this survey, the next phase of MPE's COVID-19 Outreach Workstream will include:

- Ongoing creation of educational content (articles, infographics, videos, and webinars) and translation of this content for members
- Further engagement with individual patient organisations to assess differing national needs as a result of the pandemic and how MPE can best support
- Research and investigation into the impact of COVID-19 on the diagnosis and treatment of myeloma and AL amyloidosis patients
- Training and capacity-building support for members regarding fundraising, social media, and online events
- Ongoing development of advocacy tools that can be used at national and local levels

FEEDBACK FROM MEMBERS



“MPE is supporting members a lot, and I appreciate it.” Finland

“MPE are doing a great job of supporting members and are functioning well. Organisations are supported at a high level – please continue, we are thankful to be a part of MPE.” Macedonia

“Thank you for your help and support” Romania 2

ACKNOWLEDGEMENTS

Thank you to the 28 representatives of member organisations for their time and contributions to this survey. We also thank the sponsors of our COVID-19 Outreach Workstream. This report was supported by Excerpta Medica: EMpowering Patients.



APPENDIX 1: QUESTIONS USED IN THE SURVEY

1. We collected information on the member organisation, representative, and country. Each respondent was then asked the following questions.

2. How is the COVID-19 pandemic affecting myeloma and/or AL amyloidosis patients and carers in your country? Check all that apply.

- Access to timely diagnosis is affected
- Access to treatment is affected
- Access to other healthcare services is affected
- Access to other support services is affected
- Emotional impact
- Psychological impact

Comments:

3. What is your perception or understanding of how COVID-19 has impacted the treatment of myeloma and/or AL amyloidosis patients? (Use the numbers as a scale with 1 being no impact to 5 being most affected). Select one.

- No impact on treatment
- A little impact on treatment
- Some impact on treatment
- A lot of impact on treatment
- Significant impact on treatment

Comments:

4. What information and support is your organisation providing to patients and carers during this time? Check all that apply.

- Information on website
- Information on Social Media
- Personal interviews / phone calls / videocalls / email support etc.
- Financial support
- Other (please specify)

Comments:

5. Can MPE help by translating any information for your organisation? Check all that apply.

- No, we do not need help with translations
- Yes, answers to specific questions from your organisation or patients
- Yes, information on the COVID-19 vaccines
- Yes, changes in the treatment of myeloma and AL amyloidosis due to COVID-19
- Yes, impact of COVID-19 on myeloma and AL amyloidosis patients' health and life-expectancy
- Other (Please specify)

Comments:

6. What are the specific concerns of patients and carers in your country? Do you have any specific concerns for patients and carers in your country? Check all that apply.

- I know that patients and carers have specific concerns in my country
- I have specific concerns for patients and carers in my country
- Specific concerns - Access to treatment
- Specific concerns - Access to trials
- Specific concerns - Isolation and confinement
- Specific concerns - access to information about health and wellbeing
- Specific concerns – other (Please specify)
- Specific concerns - emotional (feeling hopeless, worried, scared)
- Specific concerns - psychosocial (Psychosocial factors are around loneliness, marriage and work status, social integration, disruption to life)
- Specific concern - COVID-19 vaccine (access to the vaccine, safety of the vaccine, cost of the vaccine)
- Specific concern - Impact of COVID-19 on myeloma and AL amyloidosis patients' health and life-expectancy

Comments:

7. Are COVID-19 vaccines readily available in your country? Which vaccine/s is/are being used?

- Yes
- No

Comments:

8. If vaccination from COVID-19 is available in your country, are myeloma and AL amyloidosis patients being prioritized for vaccination?

- Yes
- No

Comments:

9. Is the vaccine free for patients?

- Yes
- No

Comments:

10. Are patients willing to get vaccinated? If not, what are the major concerns that are stopping patients from getting vaccinated?

- Yes
- No

Comments:

11. What impact has COVID-19 had on your organisation? Check all that apply.

- Staff
- Finance
- Volunteers
- Fundraising
- Programmes
- Services
- Events
- Other (Please specify)

Comments:

12. Do you have any concerns for the future of your organisation? If so, what are they?

- Yes
- No

Comments:

13. What support is your organisation receiving and has that funding changed (increased or decreased) since COVID-19 started? Check all that apply.

	Reduced	Stayed the same	Increased	Not applicable
Yes – Government	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes - other authorities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes - pharmaceutical	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes - MPE Scholarship	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes - other sources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nothing expected or not seeking support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

14. Thinking about the impact of COVID-19 on your organisation, how can MPE help support your organisation, and the work you do with patients/carers, during this time? Check all that apply.

- Information/Education support
- Translation support
- Financial support
- Advocacy support
- Social media and marketing training
- Fundraising training
- Virtual meetings and online events – training and support
- Other (Please specify:)

Comments:

15. Which of the following MPE communication channels are useful for your organisation and local patient communities? Why, do you think so?

- MPE Telegram Channel
- MPE Website
- MPE Social Media Channels

Comments:

16. Is there anything else you would like to share?



Ten years together.

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