The Myeloma UK
Patient, Family and Friends
COVID-19 Survey (2)

Summary report

October 2020

MyelomaUK

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In response to the COVID-19 pandemic, Myeloma UK are conducting a longitudinal study of three Patient and Family surveys.

This summary report shows the findings from the second survey. The first Myeloma UK patient, family and friends COVID-19 Survey summary report can be found at: **myeloma.org.uk/Patient-Family-COVID-19-Survey-Summary**

Our aim in these surveys is to understand the impact of COVID-19 on myeloma patients and their families and to use it to press for the services that are needed. This survey examines the rate of COVID infection, changes to planned treatment and shielding, and how the unfolding pandemic is affecting the myeloma community.

Survey 2 was launched after shielding measures had been paused and was open from 28 August until 16 September. Whilst the survey was live, schools re-opened in England and the 'rule of six' was introduced to combat rising cases of COVID-19 in the UK.

There were 815 responses: 621 from patients and 194 from family and friends. 68% of these respondents had completed the first survey. The high rate of repeat responders means we are confident in comparing the results of some key questions to monitor changes between the two surveys.

Impact of Survey 1

Over the past few months, Myeloma UK has used the findings from Survey 1 to improve understanding of how COVID-19 has impacted myeloma patients, family and friends and to press for the services, treatment and care that are needed.

Following this work:

- The NHS has committed to having oral alternative treatments in place until at least the end of March next year, meaning patients can still receive treatment whilst minimising their risk from COVID-19
- The Oxford University team developing a COVID-19 risk prediction model have confirmed that people in shielding groups are a key consideration and that myeloma has been included in the risk assessment model, along with other blood cancers

Key trends and new findings in Survey 2

- The rate of COVID-19 infection in patient respondents has remained at a very low level, with four patients in Survey 2 testing positive in line with three patients in Survey 1
- The availability of alternative oral treatments and other measures means patients have continued to receive treatment, with the number having their treatment plan changed staying steady since Survey 1
- Shielding continues to be a complex experience; most patients are concerned about the pausing of shielding, but many are also anxious about shielding being re-imposed
- Patients' mental health has remained stable, but family and friends are reporting a more significant burden
- Data on diagnosis during the pandemic reflects the usual pattern of diagnosis in myeloma, including the numbers of patients diagnosed via accident and emergency (A&E). However, it does not tell us how many patients are not presenting with symptoms or still struggling to receive a diagnosis
- We have obtained more detailed data on the impact on stem cell transplants (SCT), which showed a high level of concern about the impact of delay and deferral and uncertainty about when SCTs might now take place

Survey 2 findings: myeloma patients and COVID-19

What we found out

- Only four myeloma patients tested positive for COVID-19, out of a total of 198 patients who were tested
- The majority of patients (69%) tested for COVID-19 were tested prior to attending hospital for treatment
- Only 10% of those tested had experienced symptoms of COVID-19
- 66% of patients were very concerned that they would experience medical complications should they contract COVID-19
- 97% of patients are wearing face coverings, 96% are physically distancing from others, and 92% are avoiding crowded places

What this tells us

The number of patients who have tested positive for COVID-19 continues to be very small, and patients are continuing to take effective measures to protect themselves against the virus.

The NHS is providing testing capacity to help deliver COVID-safe clinical environments for myeloma patients.

Despite the low rates of infection, patients still experience a lot of anxiety about COVID-19.

> I am concerned about the severity of the medical complications I might experience with COVID-19. I know that patients with myeloma are more vulnerable to the virus. I worry about how the virus might affect me
>
> – Survey respondent

> I am already on an immuno-suppressant drug (lenalidomide) and feel very vulnerable to any additional medical complication I might pick up
>
> – Survey respondent

> I am not sure what to expect, and how severe the complications could be
>
> – Survey respondent

What needs to happen

The NHS must ensure that sufficient testing capacity is in place throughout the winter to provide a safe clinical environment for myeloma patients, including regular testing for staff. It should also continue to adapt and innovate, including looking at community-based models of service delivery where appropriate.

Impact on myeloma treatment

What we found out

- 42% of 447 patients on treatment experienced changes to their treatment plan because of the COVID-19 pandemic
- Almost a fifth of all patients have experienced impact to their supportive care, such as bone-strengthening treatments, during the COVID-19 pandemic

What this tells us

The proportion of patients whose treatment plans have changed due to COVID-19 has not changed since the first survey. This shows us that the NHS has continued to respond to ensure that the majority of myeloma patients, once diagnosed, receive their anti-myeloma treatments.

23% of patients who had their treatments changed did have concerns about the impact of using an alternative, but most found the alternatives acceptable.

What needs to happen

Oral alternatives need to remain in place as long as they are needed, and work must continue to ensure that innovations such as moving from infusions to injections (subcutaneous delivery) are adopted as quickly and as widely as possible as a standard of care.

Impact on stem cell transplants

What we found out

- 20% of first line patients and 30% of second line patients who were scheduled to have a stem cell transplant (SCT) had their transplant deferred
- 63% of those affected were concerned about the delay
- Only 43% of patients who have had a stem cell transplant deferred have received an alternative date for their SCT

What this tells us

A significant minority of patients have had their stem cell transplants delayed, and most of those patients are living with the worry about the impact this will have on their health. A large group of patients have no certainty about when their SCT will take place, suggesting that recovery plans for transplants are not reaching affected patients quickly enough. This uncertainty has a significant and worrying impact on the affected patients, and concerns us for patients who will need a SCT in the coming months.

What needs to happen

Every effort must be made to get stem cell transplantation services back to pre-pandemic levels as soon as possible. This effort must be supported by additional resource to deal with any backlog and clear clinical guidance on how to prioritise patients. Patients in every part of the country should have equal access to SCT.

Both the national and cancer alliance cancer recovery plans must address the need to get SCTs back to full capacity and data must be published to enable performance on this to be scrutinised.

Newly diagnosed patients

What we found out

In Survey 2, we were able to collect data on diagnosis during the pandemic for the first time. 31 patients who took our survey were diagnosed with myeloma after 1 February 2020.

Of these 31 patients, 48% were diagnosed in primary care, 28% in A&E, 4% were referred from another speciality, and 20% were diagnosed in another setting.

What this tells us

While the sample size in our survey is small, this data on the diagnosis of myeloma during the COVID-19 pandemic reflects the usual pattern of diagnosis in myeloma.

However, the data was not able to provide insight into how many people may not be presenting with myeloma symptoms, or how many individuals may yet be waiting for a correct diagnosis.

What needs to happen

On average, 16 people are diagnosed with myeloma every day. Over the period covered by the longitudinal study we would therefore expect around 3,344 people to be diagnosed. As it stands, we have no way of knowing how current diagnosis trends compare to this.

It is vital that we get better data on the numbers of patients presenting with myeloma and how long it is taking to be diagnosed since the COVID-19 pandemic began. This data must be published, alongside routes to diagnosis, at the earliest opportunity and every six months thereafter. We need to collect data to understand the scale of the problem to ensure we have the resources to treat patients.

Shielding and staying safe

What we found out

- 16% of patients still consider themselves to be shielding
- 55% stated they were either somewhat or very concerned about shielding being paused
- A smaller proportion of patients are finding their physical health more difficult to manage than in our previous survey. (50% of patients in Survey 2 compared with 54% of patients in Survey 1)
- The same number of patients (33%) in both Survey 1 and Survey 2 stated that they found their mental health more difficult to manage during the COVID-19 pandemic, compared to usual

What this tells us

These results confirm the findings from the first survey, which showed that the patient experience of shielding is complex. For example, the data shows that many patients remain very concerned about shielding being paused; but at the same time, some of those patients also feel apprehensive about the burden of resuming shielding.

> Pausing shielding is not relevant because I am continuing to shield until I feel safe
>
> – Survey respondent

- A significant majority of patients (71%) were either concerned about shielding being paused or effectively still shielding
- 46% of patients were concerned about shielding resuming

> We have continued to shield; it has not felt safe to stop
>
> – Survey respondent

> I am avoiding crowded places. I do have 'sensible' friends to visit and maintain social distancing
>
> – Survey respondent

What needs to happen

Since Survey 2 was run, tiered systems of restrictions have been introduced in England and Scotland, and Wales and Northern Ireland have introduced further measures to reduce the community transmission of COVID-19.

Guidance has been issued for extremely clinically vulnerable individuals by the UK Government and devolved nations administrations. However, there is still a lack of clarity on the criteria for initiating and pausing shielding, low understanding of who is accountable for shielding decisions, and scant evidence for the decisions that are made.

Clear guidance on the evidence underpinning shielding decisions and the process for initiating shielding, including who ultimately makes the decision to resume shielding, must be published as a matter of urgency.

We are still awaiting the publication of the Oxford University COVID-19 risk prediction model. This model should be published as soon as possible, making it clear how it is used to shape policy and access to services.

Family and friends

What we found out

- 69% of family and friends are finding it more difficult than usual to support their family member or friend with myeloma. This is a substantial increase on Survey 1 which was 52%
- 56% of family and friends found their own mental health more difficult to manage than usual (up 6% from Survey 1). This finding is particularly striking when compared to the patient experience where 33% of patients found managing their mental health more difficult, across both surveys
- 24% reported that if myeloma patients were to go back into shielding, family and friends would most value mental health support
- 92% of family and friends are not accessing support for themselves during the COVID-19 pandemic

What this tells us

Family and friends continue to be heavily impacted by COVID-19. They report higher levels of concern and burden than patients, and this situation seems to be worsening in some respects as time goes on. Despite this, very few are accessing support for themselves.

Family and friends commented that they needed someone outside of their family to talk to and reported a sense of demoralisation and that there was little use in seeking support. Worryingly, some family and friends also stated that support that had previously been in place for them had been stopped or paused, due to the COVID-19 pandemic.

> There seems little point (in seeking help) to be honest as everyone seems to be hiding behind guidelines and red tape
>
> – Survey respondent

> Shielding is challenging. It is difficult to navigate the new environment
>
> – Survey respondent

What needs to happen

Services which support family and friends of myeloma patients must be adequately funded and resourced. More must be done to ensure that government communication campaigns address the needs of family and friends and provide signposts to the available support. Clearer guidance on risk and shielding would also alleviate some of the psychological burden experienced by family and friends.

Myeloma UK will review our support services to ensure that we are doing all we can to support friends and family with the additional burdens of COVID-19.

Work and family life

What we found out

- 94% of family and friends living with a myeloma patient stated that having a family member or friend with myeloma made their work situation more difficult during the COVID-19 pandemic
- 27% of survey respondents were in paid employment, with almost half working from home
- 12% of patients in paid employment had been asked to return to work outside of the home after shielding was paused
- Just under 10% of survey respondents live with school-aged children. Of this group, nearly half were concerned about their child returning to school

What this tells us

Although the majority of our patients do not work or live with school-aged children, it is important to capture the experiences of those who do. These findings confirm that shielding and balancing work and family life while living with myeloma is complex and challenging.

Survey 2 was taken as children were returning to school. At this time, most children had not attended school since March, and there was no clear national guidance about school track and trace or advice on wearing face coverings. Although nearly half of respondents who lived with school-aged children (39) were concerned about them returning to school, the free text data shows that patients were also happy their child was returning to normality.

Another key theme was around spending time with grandchildren. Respondents who have grandchildren find that not being able to see them or having to physically distance from their grandchildren is very difficult.

What needs to happen?

These findings highlight the challenge facing myeloma patients and their families in balancing work, family life and living with myeloma during COVID-19. It brings sharply into focus the pressures that individuals experience when trying to navigate the necessity and benefit of returning to work and school, alongside the need to stay safe.

Patients and their family and friends are facing unavoidably difficult decisions when it comes to work and family life. The current guidelines for the clinically extremely vulnerable don't provide the clarity patients need on the level of risk they face from COVID-19, making it more difficult for patients to make informed choices about their work and family lives.

Patients are confused about what additional help they may be able to access, e.g. help with shopping, statutory sick pay or volunteer support. It is all the more important therefore that guidance is clear, flexible and evidence-based, and that changes in restrictions are communicated in good time to enable patients and those close to them to make the necessary arrangements and adjustments.

Thank you

Thank you to everyone who took the time to complete the survey. The almost 2,000 responses we have gathered from the two surveys represents the single most comprehensive picture of life with COVID-19 for myeloma patients and their family and friends in the UK.

At Myeloma UK we never forget the unique privilege of having patients and those close to them share their stories with us. We will continue to use this important resource to advocate for the services, treatment and care they need.

In distributing this survey we took steps to engage more effectively with individuals from black, Asian and minority ethnic (BAME) communities. This included reaching out to a number of cancer and health organisations who work specifically with BAME communities. Unfortunately, the number of BAME responses was still low. We know we still have more to do on this issue.

Age of patients

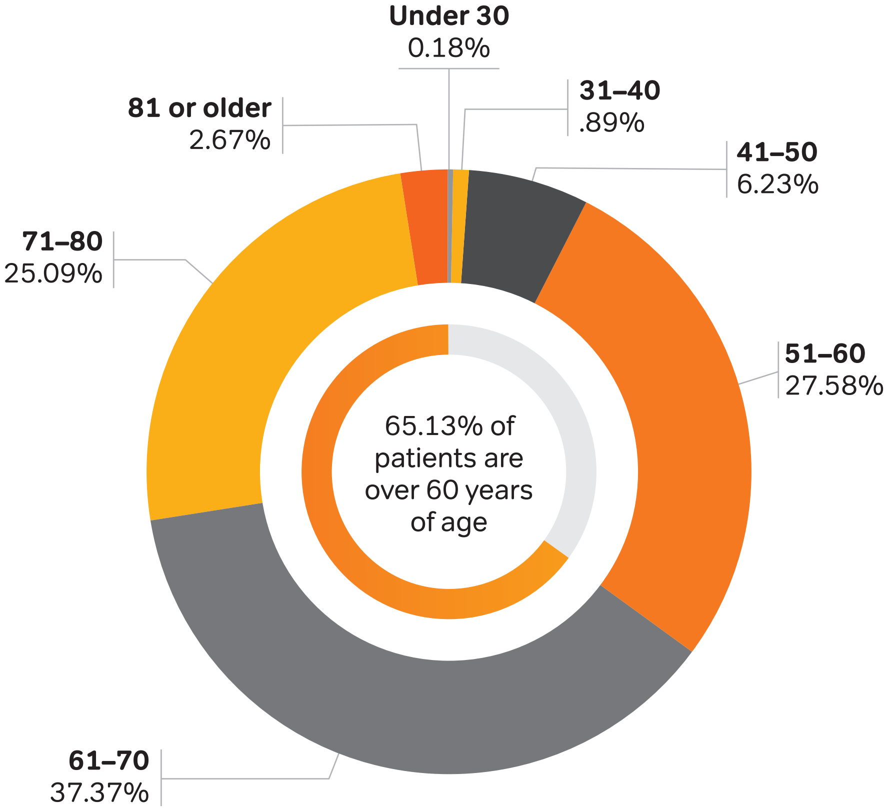

Figure 1. Age of patients (562 respondents)

Stage of myeloma treatment

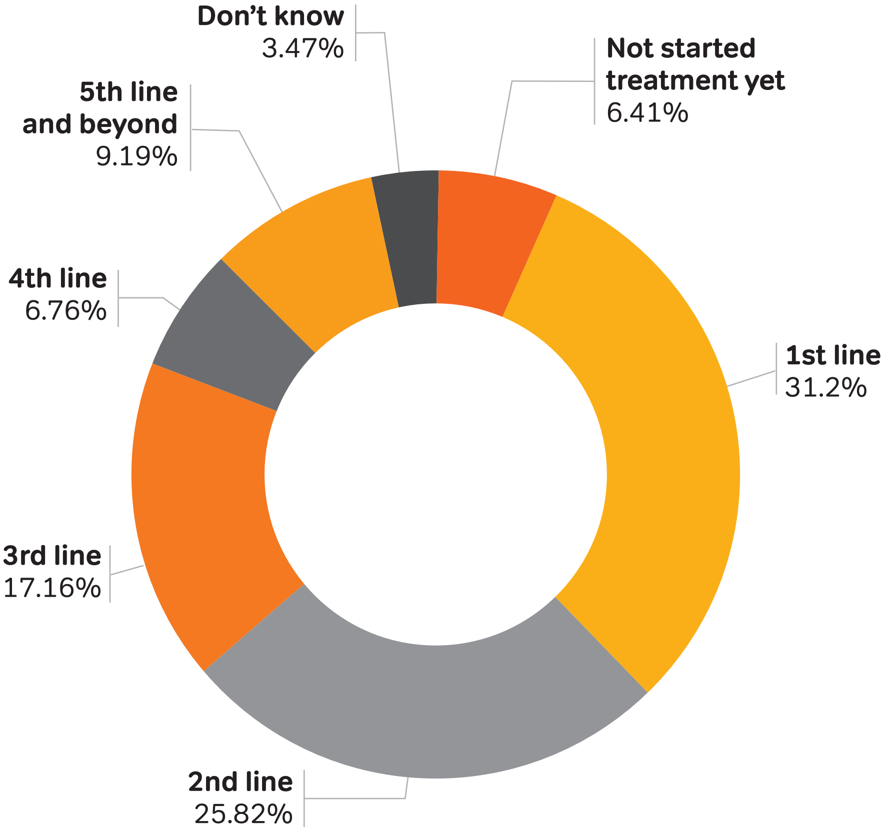

Figure 2. Stage of myeloma treatment (577 respondents)

Would you like to know more?

If you would like to know more about our advocacy work, please visit the Research and Patient Advocacy pages on our website at **myeloma.org.uk/research-and-patient-advocacy** or contact us at **policy@myeloma.org.uk**

Support and advice about myeloma and COVID-19

If you would like support or advice about myeloma or COVID-19, please visit **myeloma.org.uk**, call our free Myeloma Infoline on **0800 980 3332** (UK) or **1800 937 773** (Ireland), or contact our Ask The Nurse email service at **AskTheNurse@myeloma.org.uk**

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