



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

Summary report

July 2020



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

Myeloma patients and their families and friends have been one of the most significantly affected groups during the COVID-19 pandemic, with myeloma patients at all stages of treatment being asked to shield.

We know that COVID-19 is likely to have a lasting effect on the lives of people affected by myeloma and associated disorders. We wanted to find out what the impact had been on patients and those close to them so we can press for the treatment and care they need, and be better prepared to offer them support.

We, therefore, launched the first in a series of three Myeloma UK surveys on COVID-19 on 20 May. The survey was open for two weeks and there were 1,165 responses: 871 from patients; and 294 from family and friends.

What we found out

Shielding

- More than half of patients found it harder to manage their physical health (54%) and one third (33%) found it harder to manage their mental health while shielding
- 86 per cent of patients and 93 per cent of family and friends were concerned about the impact of shielding for a prolonged period of time
- Despite this, 60% of patients felt shielding was necessary. Only 3% did not think they had to shield or considered themselves not to be shielding

Impact on myeloma treatment

- 39% of patients had their treatment plan changed as a result of COVID-19 including the postponement of stem cell transplants, switching treatments or having treatment stopped
- 75% moved to telephone or video consultations

These findings relate to the treatment impact felt in the early stages of the pandemic in April and May. Future surveys will tell us whether there are other implications for treatment and care.

Impact on family and friends

- 80% of family and friend respondents stated they were concerned about their own mental health with 50% finding it harder to manage their mental health than usual (compared to 30% of patients)
- More than half (52%) of family and friends were finding it more difficult to support their family member or friend with myeloma
- However, 92% of family and friends were not accessing support for themselves during COVID-19

Myeloma and COVID-19

- 6% of patients said they had experienced symptoms of COVID-19
- Of 69 respondents who were tested, only three tested positive
- More than half of patients (53%) said they would want to be tested at home, if a COVID-19 test was needed
- Patients would want more support and monitoring if they were to have to self-isolate at home due to a positive COVID-19 test or COVID-19 symptoms (77% would want telephone or video consultations with their myeloma team and 46% would want an oxygen monitoring kit)

What are the main lessons?

Shielding

While shielding has been hard, most patients saw it as necessary and low numbers of myeloma patients testing positive indicates that shielding has worked.

I am missing family but understand the need to stay protected.

– Survey respondent

For myeloma patients and their families, it's not as simple as "shielding is bad, easing restrictions is good." Policy makers need to recognise that the patient experience of shielding is complex, and therefore any guidance must reflect that.

The easing of lockdown restrictions makes everything feel riskier and I feel more vulnerable.

– Survey respondent

I would like to understand more about the risk varying from different stages of myeloma... and how other factors such as age/BMI/underlying health conditions impact.

– Survey respondent

Impact on myeloma treatment

The NHS responded to ensure that patients continued to receive treatment and care for their myeloma, with only 8% of patients overall reporting that their treatment had stopped.

I am concerned it might eventually have some effect.

– Survey respondent

This response is testament to the work of clinicians and the NHS to ensure the safe delivery of chemotherapy services for as many patients as possible. It also shows the value of the oral regimens that have been substituted for other treatments that have been paused, such as stem cell transplants.

However, there is uncertainty about the long-term impact of these changes and this is worrying for patients.

I was disappointed. I felt I should have received my usual treatment.

– Survey respondent

I'm very uneasy. I should like to get treatment restarted ASAP.

– Survey respondent

Myeloma and COVID-19

Thankfully the number of respondents who tested positive for COVID-19 was very low. This response meant that we did not gather a lot of information about the experience of myeloma patients diagnosed with COVID-19.

However, some clear messages emerged about the preferences of patients should they experience symptoms or contract the virus. A majority would want to have access to testing at home and to have telephone or video consultations with their myeloma specialists while self-isolating.

Impact on family and friends

It was striking that on a number of issues family and friends were more concerned or felt more affected than patient respondents, showing how people beyond the patient are impacted by a myeloma diagnosis.

My husband is about to have his stem cell transplant, and I will have no support from family during this time due to lockdown. I am so worried he will get COVID. He will have to move out of the house when my daughter starts school in September as she doesn't understand social distancing at home. This will be really hard for us all.

– Survey respondent

Despite the burden experienced by family and friends, 92% were not seeking support for themselves.

I am concerned as to what I'd do if I caught the virus. I would not do anything to risk my husband and would need to leave but don't know where I'd go.

– Survey respondent

Our results therefore show the hidden impact of the pandemic and of shielding on family and friends. We will look more closely at this issue in future surveys.

It's difficult to support my husband when he goes for check-up appointments. He can't always remember exactly what his consultant said.

– Survey respondent

Our main worry is for the future - we don't see a time when it will be safer to be with others or in public places until a vaccination is available.

– Survey respondent

What needs to happen

We want action on the issues we have outlined to protect myeloma treatment and care, and better support myeloma patients, their family and friends while COVID-19 remains a risk.

Shielding and staying safe

Plans to pause shielding in England and Northern Ireland at the end of July have been announced, and reviews are planned for Scotland and Wales. However, there is a clear expectation that it could be reintroduced depending on future infection rates.

The key lesson to be learned from shielding is the need for a holistic approach to support and treatment for extremely clinically vulnerable people and those close to them during COVID-19; one that recognises the complexity of their experience.

- 1** Government must work with charities now to develop a holistic approach to supporting extremely clinically vulnerable people, including myeloma patients
- 2** The academic groups developing risk assessment tools should address COVID-19 risk for myeloma and other extremely clinically vulnerable groups when developing assessment tools and publish their findings
- 3** Future shielding support should specifically address the needs of family and friends

Myeloma treatment and care

- 4 Patients must have access to the best and safest treatments for their myeloma, including alternative oral regimens for as long as they are needed and sub-cutaneous administration wherever relevant.
- 5 Patients who leave the approved pathway must be able to return to the point they left if that is what their clinician recommends
- 6 Safe separation of services, COVID-19 testing and infection control must be in place for all myeloma services
- 7 Government must ensure that “real-time” data, or as close to it as possible, is published on treatment changes
- 8 New community service models must be developed, costed and commissioned, particularly for supportive treatments
- 9 Research is needed urgently into the impact of conducting consultations by telephone and video

Myeloma and COVID-19

- 10 Myeloma patients should have priority access to home testing for COVID-19 and specialised monitoring packages must be created for myeloma patients who are self-isolating with COVID-19 symptoms or following a positive test

Thank you

We are very grateful to everyone who took the time to complete the survey. The excellent response rate has given us really important evidence about how COVID-19 is affecting myeloma patients, families and friends.

With your help and support, we will now work with Government, the NHS and clinicians to achieve the actions we have set out.

While the survey means we understand the patient, family and friends experience much better, there are still questions to be answered. The situation with COVID-19 is also changing quickly and constantly. Future versions of our survey will enable us to get a more detailed understanding of the most critical issues and respond to new concerns as they arise.

Who responded to the survey

There were 1,165 responses; 871 from patients and 294 from family and friends.

Unfortunately, there were very few responses from individuals from black, Asian and minority ethnic (BAME) communities. We are sorry that our survey failed to reach people from ethnic minority communities who are affected by myeloma. We need to do better, and we are committed to changing the way we engage with BAME myeloma patients and families in future surveys to ensure their voices are heard. We will put a plan in place for future engagement and publish details of this alongside future surveys.

Age of patients

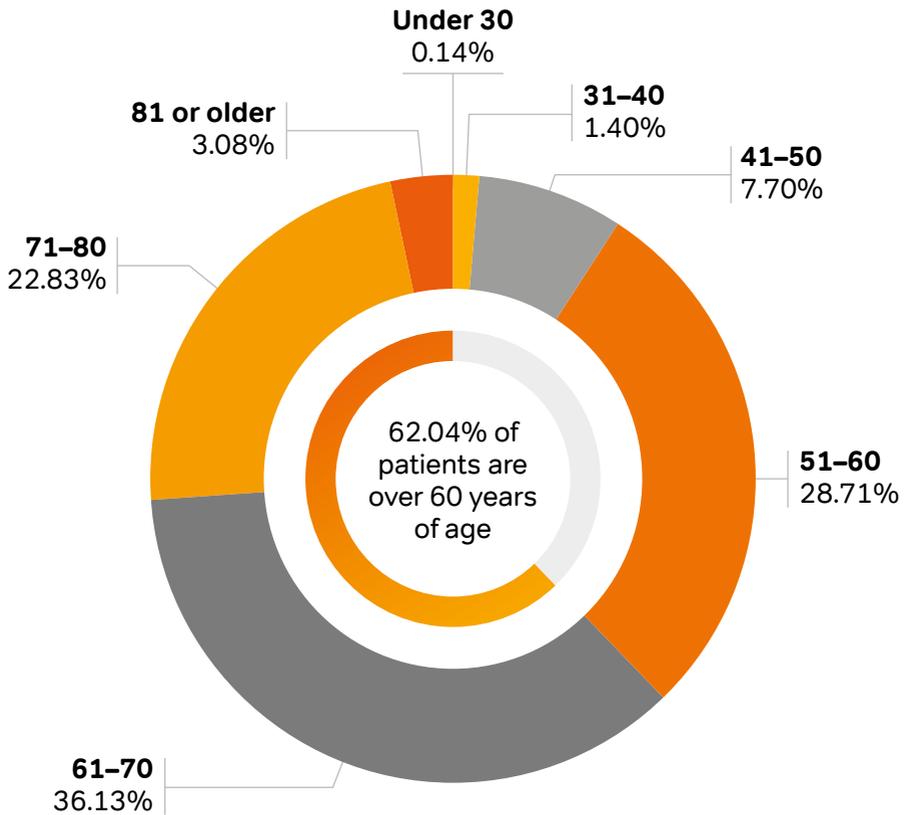


Figure 1. Age of patients (714 respondents)

Gender of patients

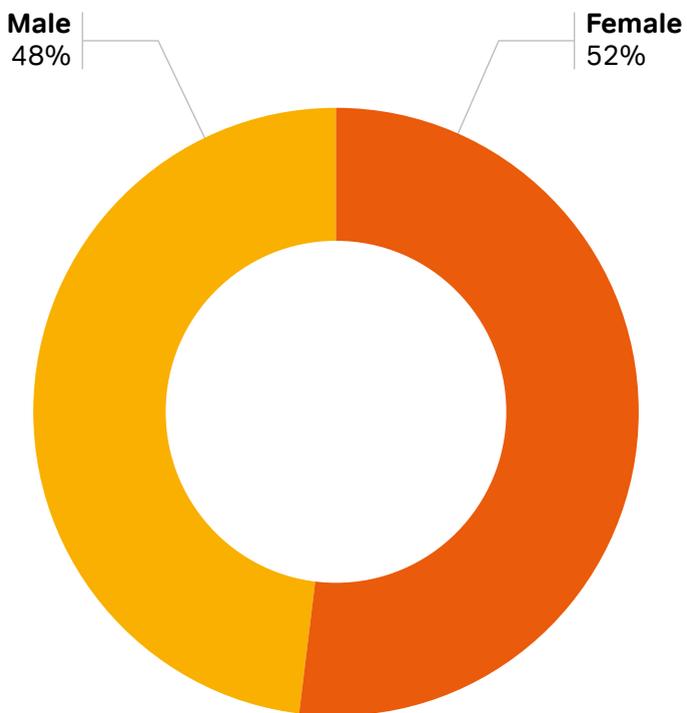


Figure 2. Gender of patients (715 respondents)

Stage of myeloma treatment

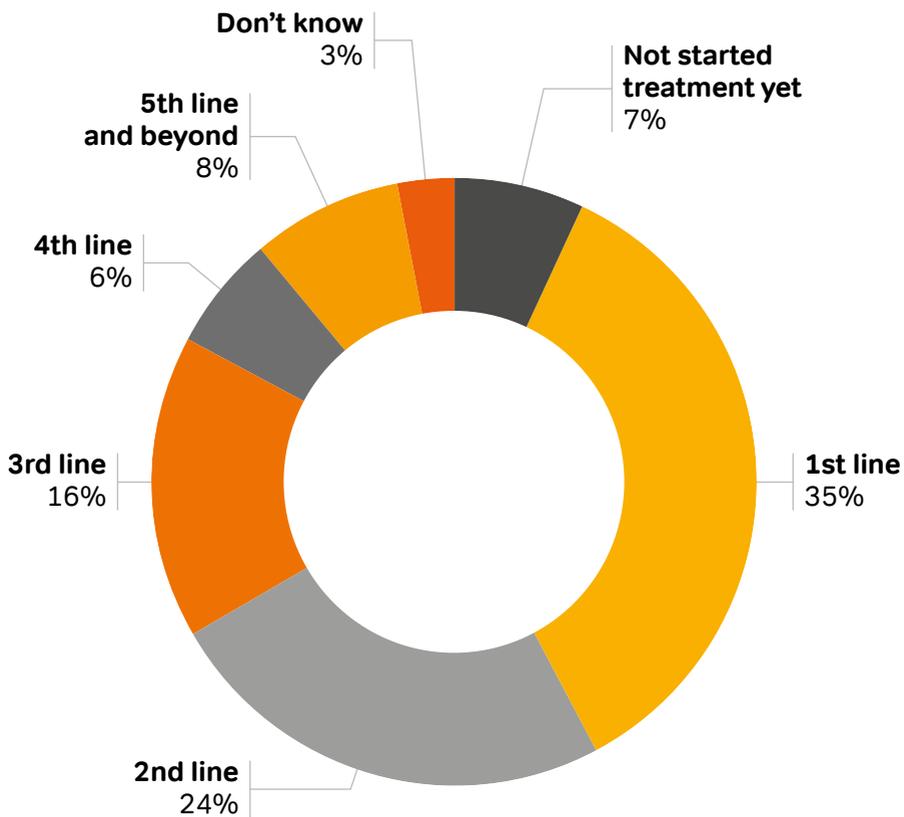


Figure 3. Stage of myeloma treatment (770 respondents)

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 and 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

Myeloma UK

22 Logie Mill, Beaverbank Business Park, Edinburgh EH7 4HG

 **0131 557 3332**

 myelomauk@myeloma.org.uk

 myeloma.org.uk