Myeloma
Patients
Europe

How do European myeloma patients feel about how, when and where they get their treatment?

Research summary

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What is myeloma?

Myeloma (also known as multiple myeloma) is a type of blood cancer that starts in the bone marrow, where blood cells are made. It affects plasma cells, a type of white blood cell that usually produces helpful proteins, called antibodies, that help fight infection. However, when myeloma develops, the bone marrow makes plasma cells that do not work properly and divide uncontrollably.

The abnormal plasma cells build up in the bone marrow and produce unhelpful proteins. This leads to symptoms including bone pain, fatigue/tiredness, infections, and kidney problems. While there is still no cure for myeloma, the development of new treatments has meant that it is often seen by medical professionals as a chronic, long-term disease for some patients.

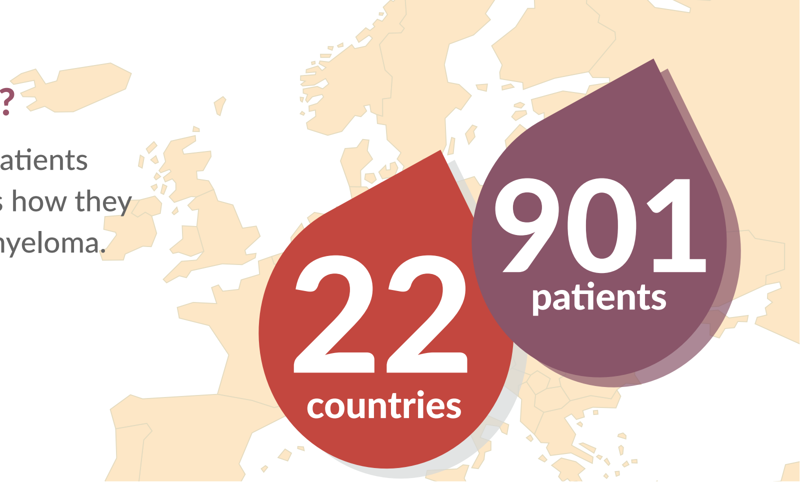
What did this study look at?

Myeloma patients may undergo many treatments and combinations of multiple treatments over time. Treatment for myeloma can bring additional burden and affect patients' daily, family and work life. Greater burden from treatment can lead to patients not being able to take their treatments as planned. It can also lead to lower treatment satisfaction and lower well-being.

This study looked at how myeloma patients feel about where, how and by whom they receive their treatments (i.e. treatment administration). It also looked at the burden of different types of administration. To date, there has been limited research done to understand patients' feelings and attitudes about myeloma treatment administration. Myeloma Patients Europe conducted this research to better understand patients' needs and to support patient-centred care and quality of life.

Who took part in this study?

In an online survey, **901** myeloma patients from **22 European countries** told us how they felt about receiving treatment for myeloma.



What were the results?

Survey participants' feelings about treatment delivery types

We asked patients how they feel about where and how they receive their myeloma treatments on a scale of 1 to 10 where 1=wholly negative and 10=wholly positive. Scores of 1-4 = negative, 5-6 = neutral, 7-10 = positive. Patients were asked about treatment types whether they had direct experience of this treatment type or not.

Patients felt most positive about **oral treatments at home.**		🙂 **83% positive** 😐 **10% neutral** ☹ **7% negative**

The most negative attitudes were for the following:

Treatments that require an **overnight stay in hospital.**		🙂 **45% positive** 😐 **24% neutral** ☹ **31% negative**
Subcutaneous (i.e. treatments that are delivered via an injection just under the skin) delivered at **home by friends or family.**		🙂 **47% positive** 😐 **22% neutral** ☹ **31% negative**
Subcutaneous delivered by the **patient themselves.**		🙂 **49% positive** 😐 **24% neutral** ☹ **27% negative**

In contrast, out-patient delivery of subcutaneous treatment was rated more positively than at-home delivery:

Out-patient (i.e during an appointment or in a medical setting) delivery of subcutaneous treatment		🙂 **62% positive** 😐 **21% neutral** ☹ **17% negative**

Patients’ feelings about the burden of receiving different treatment administration types

Patients told us about how treatment delivery types affected them in terms of burden. The burden is the workload patients must undertake to manage the delivery of that treatment and the significant impact this can have on their daily life, functioning, finances, family and well-being. In our survey, patients rated the burden of different ways of administering treatment on a scale of 0=no burden to 10=considerable burden.

Overall, burden ratings for different administration types were **relatively low** (with scores all less than or equal to 5 out of 10).

- **Intravenous (i.e. treatments given directly into a vein using a needle or catheter) and infusion (i.e. treatments given directly into a vein through a drip taking over 10 minutes) were rated as the most burdensome.**
- **Oral treatment was rated as the least burdensome.**
- **No matter the treatment type, patients reported the biggest burden from treatment was its impact on daily activities and daily life.**
- **Patients who were 65 and older reported a higher burden from all treatment types.**

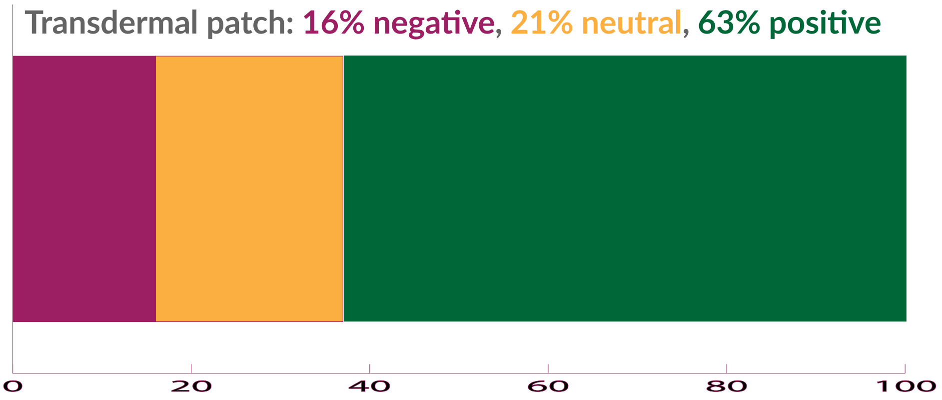
Patients’ feelings about the most important features of treatment

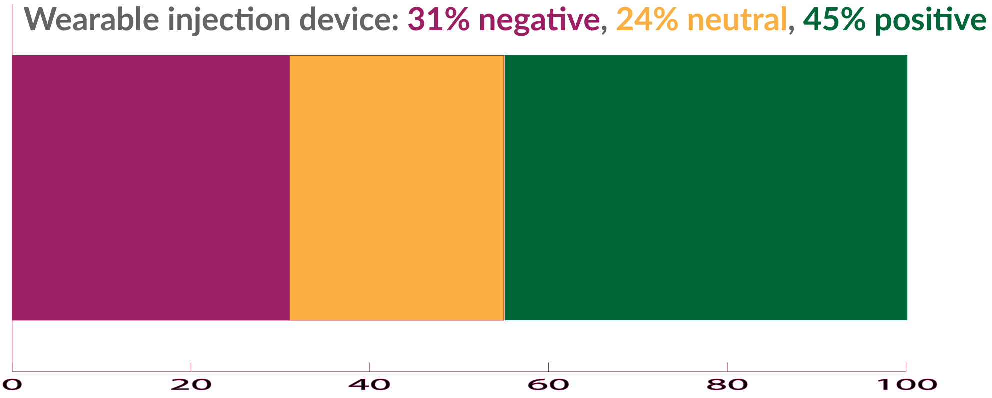
Patients' top five most important aspects of treatment were:

1. **The physical impact of treatment**
2. **The impact on day-to-day activities**
3. **The chance to regularly see health professionals whilst receiving treatment**
4. **Avoiding a hospital stay as an in-patient**
5. **The impact on family life**

Patients' feelings about potential new treatment delivery modes

We asked patients about potential future methods of delivering myeloma treatment that are being developed and tested in clinical trials. Patients had mixed feelings towards receiving treatment via a transdermal (i.e. applied to the skin) patch and through a wearable injection device (i.e. a device that is applied to the skin, delivers an injection through the skin and is then removed). There were more positive ratings for a transdermal patch.





Patients were more positive about trying a potential myeloma treatment delivered by a patch on the skin than they were to try a wearable injection device.

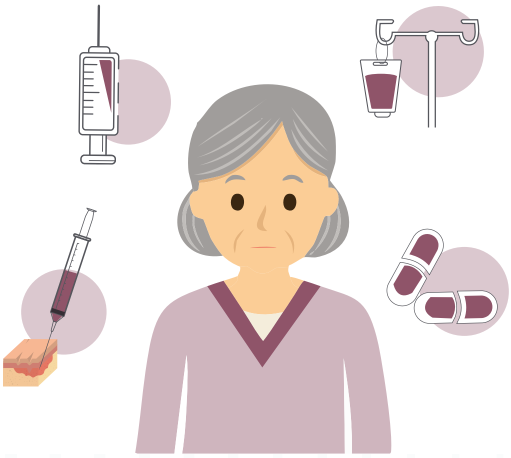
What do the results mean?

Myeloma patients have different preferences and feelings about how they receive their myeloma treatments. Treatment planning should be individualised wherever possible to take patients' preferences and needs into account.

Myeloma patients feel positively about oral treatments at home but were less positive about more invasive (i.e. where treatment enters the body by puncturing the skin) treatments at home. Patients value professional administration and clinical settings for injection-based treatments.

Some patients will feel uncertain about home-based treatments, and it may not be the right option for everyone. For any at-home treatments, patients should be provided with education and support so that they can feel comfortable and confident.

For patients, knowing how other patients have felt about different treatment types and locations can help inform decision-making and help make practical preparations to reduce the burden of treatments.



Limitations

Our study participants were myeloma patients who responded to our social media and outreach efforts. This means they are a self-selecting group of people who wanted, and felt well enough, to take part and there could be unknown differences compared to the wider community of myeloma patients. The survey questions included short descriptions of treatment types and were not about specific medications. Real-world treatment attitudes and decisions will also be based on how effective and safe specific treatments are.

About this report

Who conducted this study?

Myeloma Patients Europe (MPE) conducted this research study. MPE is an umbrella organisation of myeloma and AL amyloidosis patient groups across Europe. MPE currently has 52 members based in 33 countries.

Our mission is to drive advocacy by empowering the myeloma community through research, education and collaboration.

Are there plans for further studies?

Myeloma patients may receive many different treatments throughout their care. Patients' real-world experiences of treatments tell us how treatments work in everyday life. Myeloma Patients Europe (MPE) wants to hear from myeloma patients about their experiences with some particular treatments:

- Bispecific antibodies (such as teclistamab or elranatamab)
- CAR T-cell therapy (such as cilta-cel or ide-cel)
- Antibody–drug conjugates (such as belantamab mafodotin).
- Selinexor (a selective inhibitor of nuclear export)

If you have had any these treatments and would be willing to share your experiences with us, please register your interest. Your insights are incredibly valuable and your participation will help us shape research, policy and future myeloma care across Europe.

Where can I go for further information?

For the full study paper, click here, or if you have a specific question you can contact us: research@mpeurope.org

Who funded this study?

We would like to thank Pfizer, Roche, Sanofi and Takeda for providing funding that helped support this study. The funders had no role in data collection, interpretation, analysis or reporting.

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