



# National Cancer Patient Experience Survey 2018

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Deciding the best treatment for you

February 2021



## The National Cancer Patient Experience Survey

The National Cancer Patient Experience Survey (NCPES) asks patients about their experience with NHS cancer care in England. A national report is publicly available which summarises the findings for cancer patients on average. However, as there may be differences in patient experience of care across cancer types Myeloma UK have analysed the NCPES survey data to focus on the myeloma patient experience. We have also made comparisons with the experience of other cancer patients to see if the findings are consistent with other cancers in general.

### Survey participants

The 2018 NCPES questionnaire was sent to all adults (aged 16+) who had a confirmed primary diagnosis of cancer and were discharged from an NHS Trust for cancer related treatment between April-June 2018. The overall response rate was 64%, or 73,817 participants, of which 4,966 were Myeloma patients.

**Myeloma patients in this survey are older and more likely to be male than patients with other cancers in general (Table 1).**

Age	Myeloma <sup>1</sup> (N=4,966)	Other cancers <sup>1</sup> (N=68,851)
16-24	0.0	0.4
25-34	0.1	1.1
35-44	0.8	3.2
45-54	5.7	10.5
55-64	19.0	21.6
65-74	38.1	35.7
75-84	30.1	23.0
85+	6.2	4.5
Sex		
Male	59.2	46.5
Female	40.8	53.5
Ethnicity		
Black, Asian and minority ethnic	9.3	7.9
White	84.7	81.5
Not specified or suppressed <sup>2</sup>	5.9	10.5

**Table 1.** Percentage of myeloma and other cancer patients in the NCPES 2018 survey by self-reported age, sex, and ethnicity

<sup>1</sup> Totals may not sum to 100% exactly due to rounding.

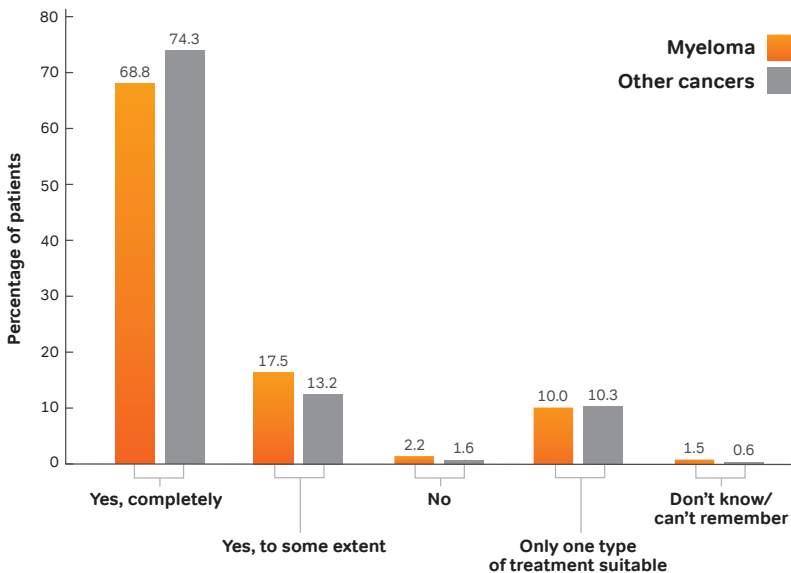
<sup>2</sup> NCPES suppresses results for categories where there are a small number of respondents to minimise the risk of individuals being identified.

## Deciding the best treatment for you

This section summarises results of patient experiences deciding on the best treatment for them.

### Before your cancer treatment started, were your treatment options explained to you?

The vast majority of myeloma patients received an explanation of their treatment options before their cancer treatment started (Figure 1). However, only two thirds of myeloma patients compared to three quarters of other cancer patients in general received complete explanations of treatment options prior to starting cancer treatment.



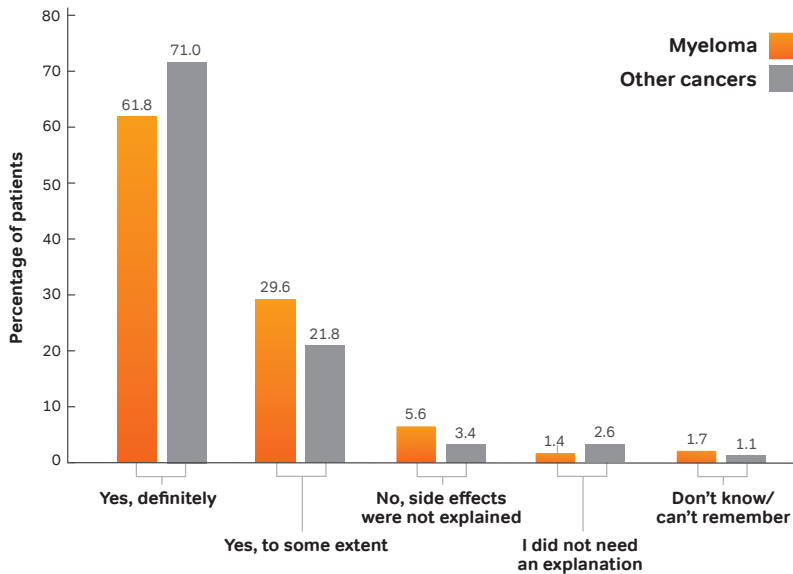
**Figure 1.** Percentage of myeloma and other cancer patients by whether treatment options were explained to them before their cancer treatment started.<sup>1</sup>

<sup>1</sup> Totals may not sum to 100% exactly due to rounding.

Myeloma UK is pleased that the vast majority of patients are told about treatment options before starting treatment but also notes that not all patients are getting complete explanations.

## Were the possible side effects of treatment(s) explained in a way you could understand?

Whilst the majority of myeloma patients received an explanation of treatment side effects, only 6 in 10 received a full explanation compared to 7 in 10 patients of other cancers in general (Figure 2).

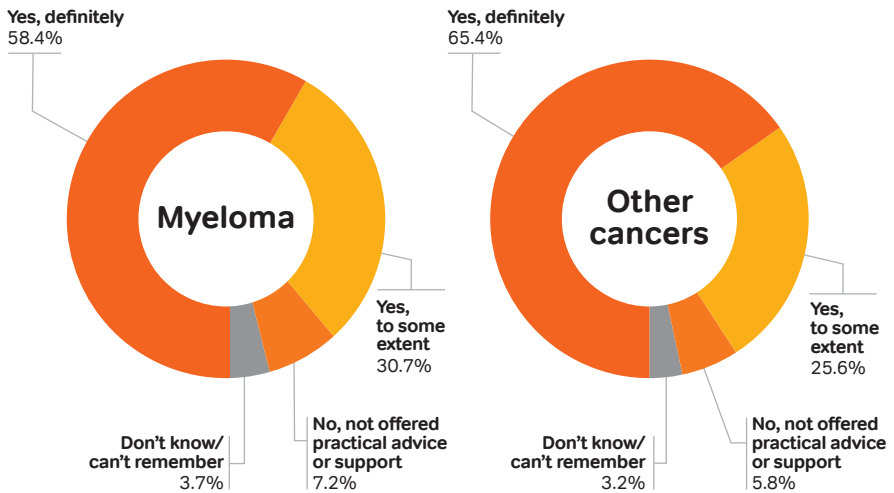


**Figure 2.** Percentage of myeloma and other cancer patient by whether side effects were explained in an understandable way.

Whilst Myeloma UK is pleased that the majority of patients are given some explanation of treatment side effects we are disappointed that a third of patients do not receive an explanation which is fully understandable.

## Were you offered practical advice and support in dealing with the side effects of your treatment(s)?

The majority of myeloma patients were offered some practical advice and support in dealing with side effects. However, only 58% of myeloma patients were “definitely” offered practical advice and support compared to 65% of other cancer patients in general. (Figure 3).

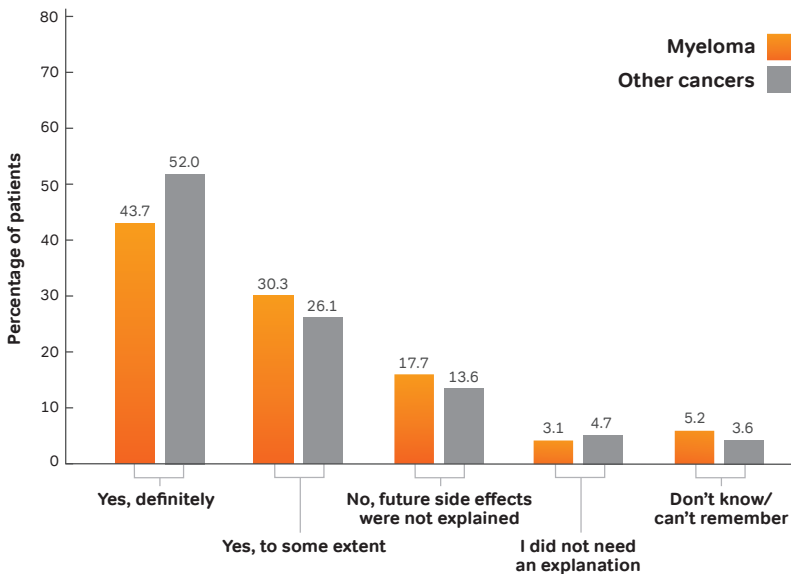


**Figure 3.** Percentage of myeloma and other cancer patient by whether practical advice and support was offered in dealing with the side effects of treatment.

Myeloma UK is pleased that the majority of patients are offered practical advice and support we recognise that many patients are only offered advice and support to some extent.

## Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than right away?

Three quarters of myeloma patients received some explanation of future side effects (Figure 4). However, myeloma patients were less likely to receive full explanations on future side effects compared to other cancer patients in general.

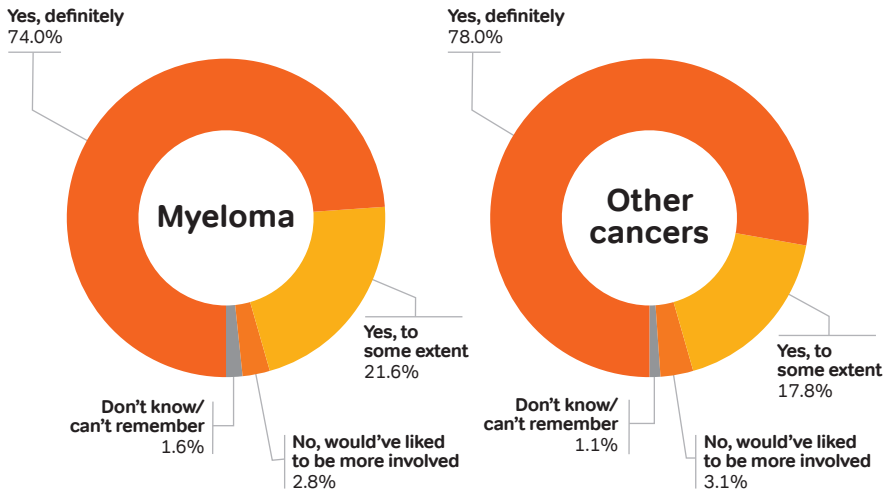


**Figure 4.** Percentage of myeloma and other cancer patient by whether they were told about future side effects of their treatments.

Myeloma UK is disappointed that almost one in five myeloma patients are not told of future side effects before they start treatment. These can be detrimental to patients' wellbeing, and impact family life, jobs and quality of life.

## Were you involved as much as you wanted to be in decisions about your care and treatment?

The vast majority of myeloma patients were involved in decisions about care and treatment (Figure 5). Similar to other cancer patients in general, only 3% of myeloma patients reported that they were not involved in decisions about their care and treatment but would have liked to have been more involved.



**Figure 5.** Percentage of myeloma and other cancer patient by whether they were involved in care and treatment decisions as much as they wanted to be.

Myeloma UK is glad that the majority of myeloma patients are involved in care and treatment decisions with three quarters of myeloma patients definitely involved in decisions about care and treatment as much as they want to be.



## Patient experience of deciding on the best treatment by demographic characteristics

The percentage of myeloma patients by age, sex, and ethnicity who had a positive experience in deciding on the best treatment for them is shown in Table 2.

Age	Treatment options were explained completely		Side effects definitely explained in an understandable way		Definitely offered practical advice and support dealing with side effects	
	Myeloma	Other cancers	Myeloma	Other cancers	Myeloma	Other cancers
<b>16-54</b>	79.1	79.5	70.8	74.6	63.6	63.6
<b>55-64</b>	76.8	82.1	65.3	73.3	57.4	65.6
<b>65-74</b>	76.6	84.5	63.6	73.6	58.4	67.1
<b>75-84</b>	76.2	83.8	58.9	71.5	58.0	65.1
<b>85+</b>	72.7	79.4	58.1	67.0	58.5	57.9
<b>Sex</b>						
<b>Male</b>	77.5	82.5	63.9	72.7	59.4	65.0
<b>Female</b>	75.0	83.1	60.8	73.1	57.1	65.7
<b>Ethnicity</b>						
<b>Black, Asian and minority ethnic</b>	74.5	80.2	63.6	72.3	56.5	64.4
<b>White</b>	76.4	83.1	62.6	73.0	58.7	65.4

**Table 2.** Percentage of myeloma and other cancer patients with a positive experience in deciding on the best treatment by age, sex, and ethnicity.

Table continues overleaf...

Age	Definitely told about future side effects		Definitely involved in care and treatment decisions as much as you wanted to be	
	Myeloma	Other cancers	Myeloma	Other cancers
<b>16-54</b>	54.9	53.1	75.5	73.2
<b>55-64</b>	48.3	54.4	72.2	76.1
<b>65-74</b>	45.3	56.2	75.0	80.0
<b>75-84</b>	41.4	54.1	73.8	80.2
<b>85+</b>	40.4	48.7	72.1	77.1
<b>Sex</b>				
<b>Male</b>	48.0	57.3	75.8	78.5
<b>Female</b>	40.9	52.1	71.3	77.6
<b>Ethnicity</b>				
<b>Black, Asian and minority ethnic</b>	49.0	56.2	66.1	72.0
<b>White</b>	44.6	54.1	75.1	78.7

**Table 2 (continued).** Percentage of myeloma and other cancer patients with a positive experience in deciding on the best treatment by age, sex, and ethnicity.

## Age

Younger myeloma patients had a more positive experience when it came to understanding side effects than older adults: They were more likely to definitely have had side effects explained in an understandable way and have been told about future side effects than older patients which is similar to other cancer patients in general.

Myeloma UK notes that older patients have a poorer experience of being told about side effects whilst making treatment decisions than younger patients.

## Sex

Female myeloma patients had a less positive experience than male patients, they were less likely to definitely receive understandable explanations of side effects or to be told about future side effects which is similar to other cancer patients in general. Female myeloma patients were also less likely to report definitely being involved in care and treatment decisions as much as they wanted to be.

Myeloma UK is disappointed by the observation that female myeloma patients have a poorer experience of being told about side effects than male myeloma patients and are less likely to be involved in care and treatment decisions than male patients.

## Ethnicity

Black and ethnic minority myeloma patients were less likely than white patients to report definitely being involved in care and treatment decisions as much as they wanted to be which is similar to other cancer patients in general.

Myeloma UK notes that the experience of being told about side effects in deciding on a treatment is worse for older patients and female patients. We are also disappointed that only two thirds of black and minority patients are definitely involved in care and treatment decisions compared to three quarters of white myeloma patients which is a larger disparity compared to other cancers in general.

## Summary

- The vast majority of myeloma patients received an explanation of their treatment options before their cancer treatment started, although 1 in 5 patients did not get a full explanation
- The majority of myeloma patients received an explanation of treatment side effects, although only 6 in 10 received a full explanation.
- The majority of myeloma patients were offered some practical advice and support in dealing with side effects.
- A lower proportion of black and minority patients are definitely involved in care and treatment decisions than white myeloma patients.
- Older myeloma patients and female myeloma patients have a less positive experience deciding on treatment compared to younger myeloma patients and male myeloma patients.

## Why have we provided these reports?

It is important to understand and look at the most recent national data on the issues that are relevant to myeloma patients and compare these against other cancers. In doing so, we can identify best practice and areas where improvements are needed.

Myeloma UK uses this evidence to advocate for improvements in diagnosis, treatment and care for myeloma patients.

This NCPES report is the last in the series. If you wish to read the other reports, please see our website at:

**[myeloma.org.uk/research-and-patient-advocacy/2018-national-cancer-patient-experience-survey-results](https://myeloma.org.uk/research-and-patient-advocacy/2018-national-cancer-patient-experience-survey-results)**

## Acknowledgements

The data from the National Cancer Patient Experience Survey were obtained from the UK Data Service:

NHS England, Quality Health. (2019). National Cancer Patient Experience Survey, 2018. [data collection]. UK Data Service. SN: 8570, <https://doi.org/10.5255/UKDA-SN-8570-1>

## Would you like to know more?

You can read more about this project on our website:  
[myeloma.org.uk/research-and-patient-advocacy/health-services-research-programme](https://myeloma.org.uk/research-and-patient-advocacy/health-services-research-programme)

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