



National Cancer Patient Experience Survey 2018

Finding out what was wrong with you

November 2020



The National Cancer Patient Experience Survey

The NCPES survey 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 ¹ (N=4,966)	Other cancers ¹ (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 ²	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.

¹ Totals may not sum to 100% exactly due to rounding.

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

Finding out what was wrong with you

This section summarises results of patient experiences of finding out what was wrong with them.

When you were first told that you had cancer, had you been told you could bring a family member or friend with you?

Just over two thirds of myeloma patients were told that they could bring a family or friend with them compared to three-quarters of other cancer patients in general (Figure 1).

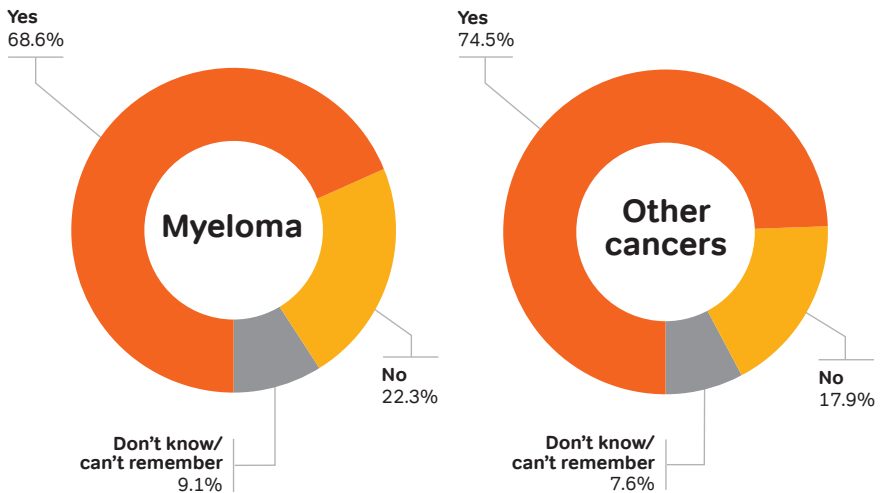


Figure 1. Percentage of myeloma and other cancer patients by whether they were told that they could bring a family member or friend with them.

Myeloma UK is disappointed that one third of myeloma patients had either not been told, or were unsure if they had been told, that they could bring someone with them.

How do you feel about the way you were told you had cancer?

Eight out of ten myeloma patients felt that they were told sensitively that they had cancer (Figure 2). A slightly higher proportion of myeloma patients compared to other cancer patients in general felt that they could have been told more sensitively that they had cancer.

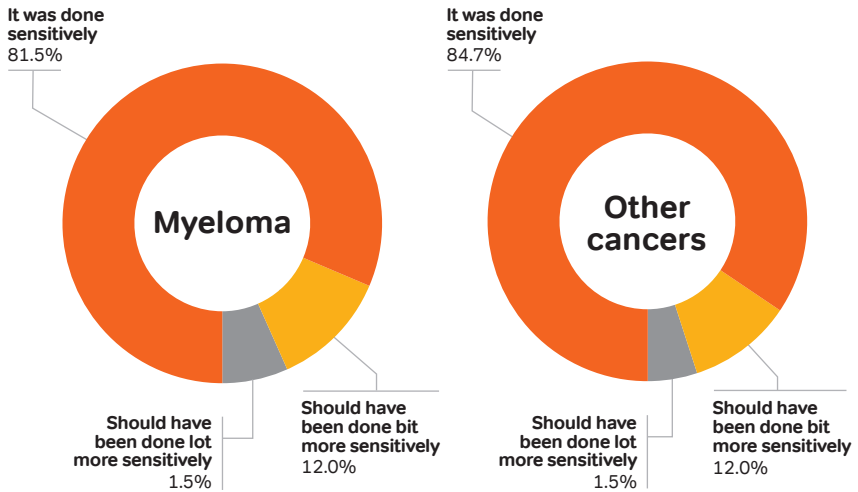


Figure 2. Percentage of myeloma and other cancer patient by how they felt about the way they were told they had cancer.

Myeloma UK is pleased that the majority of patients are being told about their cancer in a sensitive way. However, these findings demonstrate that for 1 in 5 myeloma patients the way they were informed of their cancer could have been done better.

Did you understand the explanation of what was wrong with you?

One in twenty myeloma patients did not understand the explanation of what was wrong with them. The proportion of myeloma patients who completely understood the explanation was lower than that of other cancers in general. Whilst just over half of myeloma patients completely understood the explanation, just over a third only understood some of it (Figure 3).

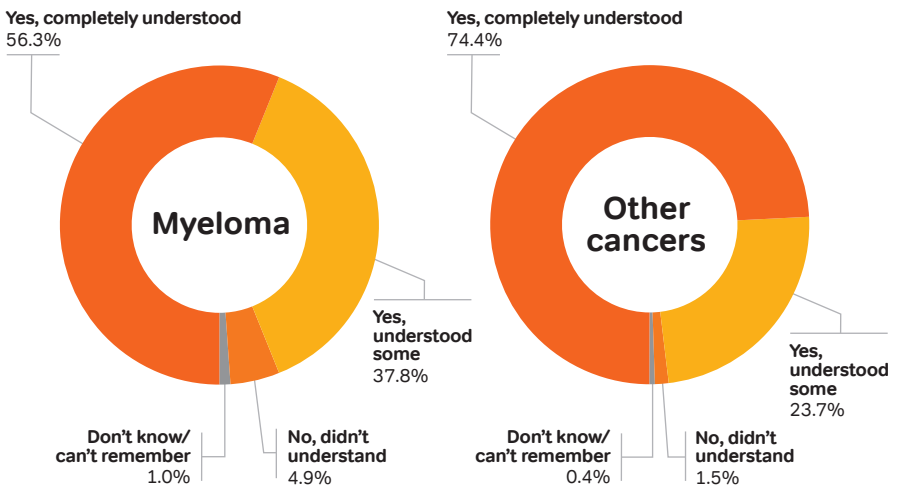


Figure 3. Percentage of myeloma and other cancer patient by their understanding of the explanation of what was wrong with them.

Myeloma UK is very disappointed that just under half of patients are not receiving a completely understandable explanation of what is wrong with them.

When you were told you had cancer, were you given written information about the type of cancer you had?

Two thirds of myeloma patients were given easy to understand written information about the type of cancer that they had which was similar to other cancer patients in general (Figure 4). One in ten myeloma patients received difficult to understand written information and another one in ten myeloma patients did not receive any written information.

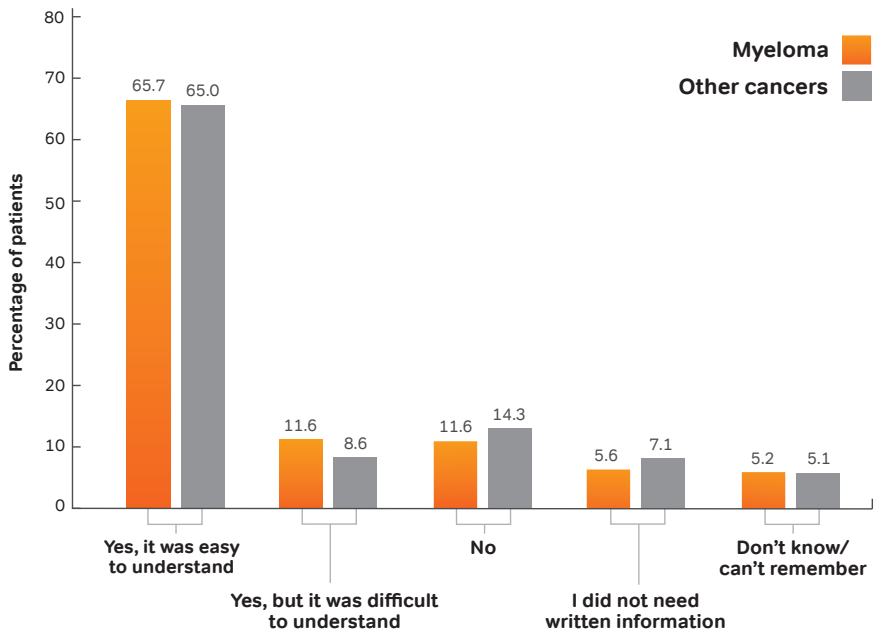


Figure 4. Percentage of myeloma and other cancer patient by whether they received understandable written information about the type of cancer they had.

Whilst Myeloma UK is pleased that the vast majority of patients are receiving written information about myeloma, we are disappointed that one in five patients are not being given understandable written information.

Patient experience of finding out what was wrong with them by demographic characteristics

The percentage of myeloma patients by age, sex, and ethnicity who had a positive experience with finding out what was wrong with them is shown in Table 2.

Age	Told you could bring someone with you		Told you had cancer sensitively		Completely understood explanation of what was wrong		Given easy to understand written information about the type of cancer	
	Myeloma	Other cancers	Myeloma	Other cancers	Myeloma	Other cancers	Myeloma	Other cancers
16–54	65.3	67.7	75.7	81.1	50.5	66.0	63.3	67.6
55–64	65.4	72.4	77.4	82.4	49.5	72.1	67.8	69.6
65–74	67.6	76.1	80.1	85.1	56.5	76.5	70.4	72.2
75–84	72.1	78.2	85.9	87.7	61.5	78.6	71.1	69.6
85+	71.7	77.3	88.1	90.3	57.1	75.8	70.5	63.6
Sex								
Male	70.0	75.5	82.4	84.9	58.0	74.7	70.0	71.7
Female	66.6	73.7	80.3	84.6	53.8	74.1	69.1	68.5
Ethnicity								
Black, Asian and minority ethnic	71.7	75.8	84.4	82.5	56.9	71.4	68.1	66.8
White	68.2	74.3	81.1	84.9	55.9	74.7	69.9	70.4

Table 2: Percentage of myeloma and other cancer patients with a positive experience finding out what was wrong with them by age, sex, and ethnicity.

Age

The myeloma patient experience of finding out what was wrong was similar to other cancers in general with younger patients having a less positive experience. Younger myeloma patients were less likely to be told they could bring someone with them compared to older patients. Older patients were more likely to report having been told of their cancer sensitively than younger patients. In addition, younger myeloma patients were less likely to have completely understood the explanation of what was wrong compared to older patients, and younger patients were less likely to report receiving easy to understand written information than older patients.

Sex

Similar to other cancers in general, female myeloma patients were less likely to have been told they could bring someone with them compared to male patients. However, female myeloma patients were less likely to have completely understood the explanation of what was wrong with them compared to male myeloma patients.

Akin to other cancers in general the proportion of myeloma patients who felt they had been told of their cancer sensitively was similar for males and females. The proportion of male and female myeloma patients receiving easy to understand written information was similar unlike other cancers in general where a lower proportion of females received easy to understand written information.

Ethnicity

A similar proportion of black and minority and white patients were told they could bring someone with them, received a completely understandable explanation, and received easy to understand written information. Unlike other cancers in general, black and minority myeloma patients were more likely report having been told of their cancer sensitively than white myeloma patients.

Myeloma UK recognises there are some differences in experience in finding out what was wrong across groups particularly across ages. We note that the demographic differences in experiences of finding out what was wrong for myeloma patients and other cancers in general are, for the most part, similar.

Summary

- Just over two thirds of myeloma patients had been told that they could bring a family or friend with them when they first found out they had cancer
- The majority of myeloma patients felt that they were told sensitively that they had cancer
- Over half of myeloma patients completely understood the explanation of what was wrong with them, whereas just over a third only understood some of it, and 5% did not understand the explanation
- Two thirds of myeloma patients were given easy to understand written information about myeloma
- One in ten myeloma patients received difficult to understand written information about myeloma and another one in ten myeloma patients did not receive any written information about myeloma
- Younger myeloma patients have a less positive experience than older myeloma patients in finding out what was wrong

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

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