



National Cancer Patient Experience Survey 2018

Diagnostics

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.

Diagnostics

The majority of respondents to the survey were newly diagnosed. Indeed, six out of ten myeloma patients, compared to nine out of ten other cancer patients had a diagnostic test in the past year. The following pages summarize the responses of those newly diagnosed patients about their diagnostic test experience.

Beforehand, did you have all the information you needed about your test?

Similar to other cancers in general, the majority of myeloma patients had all the information they needed about their diagnostic test beforehand (Figure 1). One in twenty patients would have liked more information.

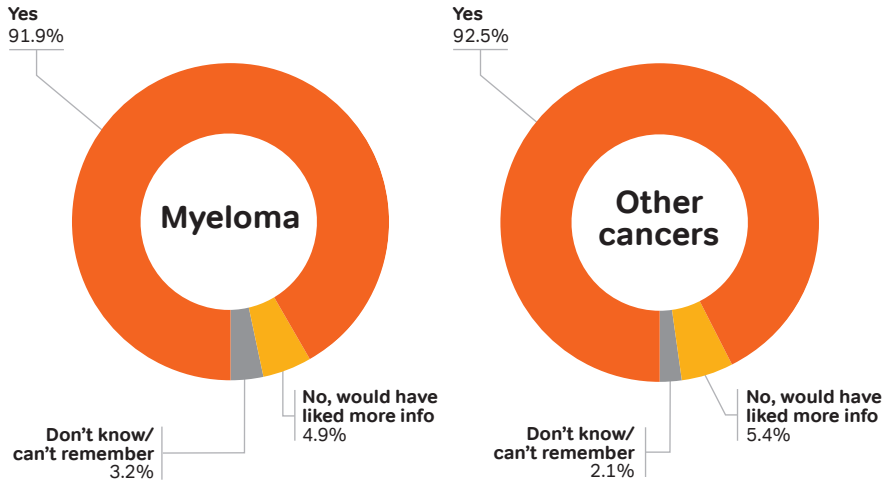


Figure 1. Percentage of myeloma and other cancer patients who had information needed about their diagnostic test.

Myeloma UK is pleased that nine out of ten myeloma patients have all the information they need about their diagnostic test beforehand.

Overall, how did you feel about the length of time you had to wait for your test to be done?

Myeloma patients were more likely to feel that the length of time they had to wait for their test to be done was about right compared to other cancers in general (Figure 2).

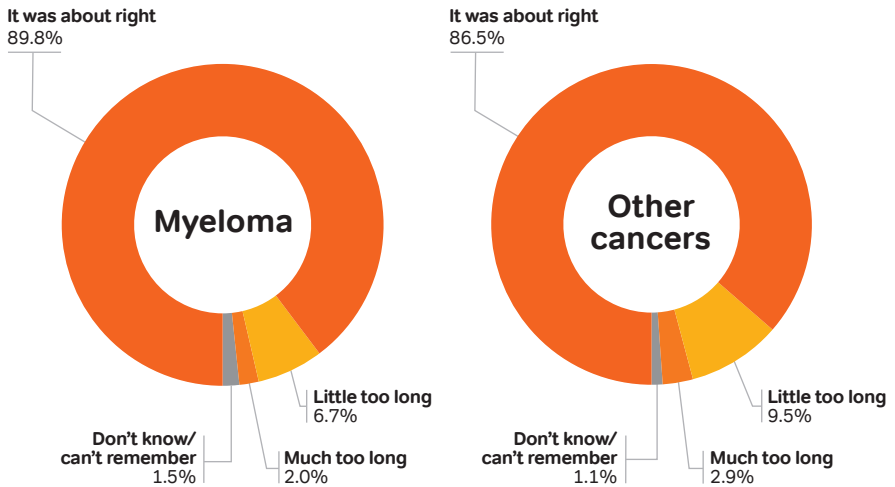


Figure 2. Percentage of myeloma and other cancer patient by how they felt about the waiting time for the diagnostic test to be done.

Although there are still some patients that find the length of time they have to wait for a diagnostic test to be too long, Myeloma UK is glad that for the vast majority of patients, the wait time is about right.

Were the results of the test explained in a way you could understand?

Similar to other cancers in general, three quarters of myeloma patients felt their test results were explained in a way that they could completely understand (Figure 3). One in five myeloma patients felt that the results were explained, but not in a fully understandable way. A very small minority of patients did not understand the explanation or did not receive an explanation of their diagnostic test results.

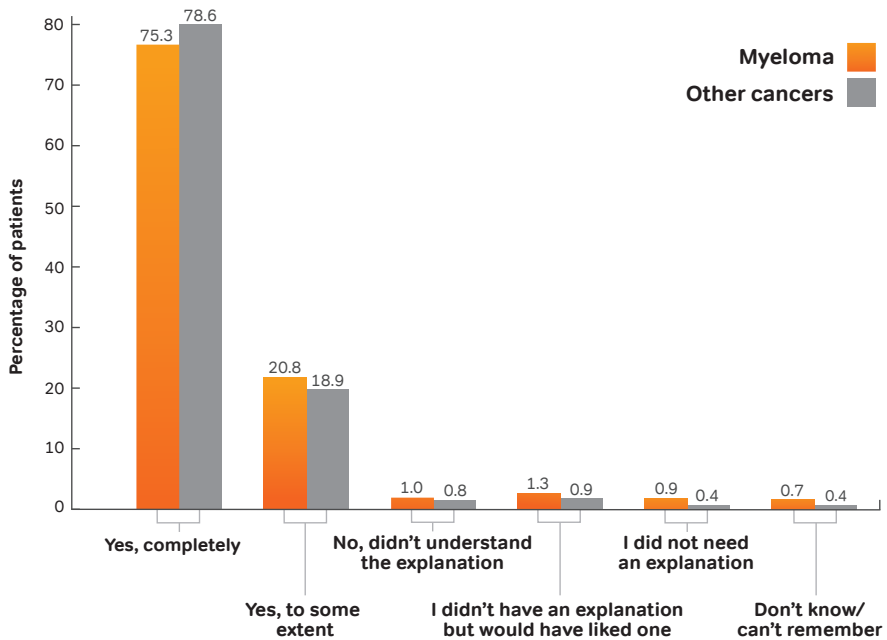


Figure 3. Percentage of myeloma and other cancer patients by how they thought the test results were explained.

Whilst Myeloma UK is glad that the vast majority of myeloma patients are receiving an explanation of their test results, we are concerned that so many patients are not receiving an explanation that they fully understand.

Patient experience of diagnostics by demographic characteristics

The percentage of myeloma patients by age, sex, and ethnicity who had a positive experience with diagnostics is shown in Table 2.

Age	Had all the information needed before diagnostic test		Length of waiting time for test to be done was about right		Test results were completely explained in an understandable way	
	Myeloma	Other cancers	Myeloma	Other cancers	Myeloma	Other cancers
16–54	93.6	60.1	71.5	77.6	72.3	79.3
55–64	36.9	55.1	77.1	82.7	76.0	79.7
65–74	41.7	58.2	80.1	85.3	76.3	80.4
75–84	46.4	64.3	83.9	85.9	73.6	78.7
85+	44.4	64.7	89.1	88.2	70.5	76.2
Sex						
Male	43.5	62.2	81.6	83.4	77.0	77.3
Female	38.5	57.0	79.1	84.2	71.7	81.5
Ethnicity						
Black, Asian and minority ethnic	31.0	52.0	72.8	77.2	64.5	73.1
White	42.9	60.4	81.5	84.6	76.0	80.4

Table 2. Percentage of myeloma and other cancer patients with a positive diagnostic experience by age, sex, and ethnicity.

Age

Similar to other cancers in general, myeloma patients over the age of 85 were less likely to report having had all the information they needed before a diagnostic test compared to younger patients. Whilst there were some age differences for other cancers, the percentage of myeloma patients who felt the wait time for their diagnostic test was about right and who received an explanation of their test results that they completely understood, was across similar ages.

Sex

The diagnostic experience is similar for male and female myeloma patients.

Ethnicity

Similar to other cancer patients in general, black and minority myeloma patients have a less positive diagnostic experience than white myeloma patients. Black and minority patients are less likely to have had all the needed information before a diagnostic test, are less likely to think the waiting time for a diagnostic test is about right and are less likely to have received an explanation of their test results that they can completely understand.

Myeloma UK is concerned that black and minority myeloma patients have a poorer diagnostic experience. Only two thirds of black and minority patients (compared to three quarters of white patients) are receiving an explanation of their test results in a way that they could completely understand.

Summary

- Nine out of ten myeloma patients had all the information needed about their diagnostic test beforehand
- Nine out of ten myeloma patients felt that the amount of time they had to wait for their test to be done was about right
- Only three-quarters of myeloma patients received an explanation of their test results that they could completely understand
- There were clear ethnic differences in myeloma diagnostic care, with black and minority patients having a poorer diagnostic experience compared to white patients
- The myeloma diagnostic experience was similar for men and women, although similar to other cancers, older myeloma patients were less likely to have all the needed information before a diagnostic test compared to younger myeloma patients

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

Myeloma UK

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

📞 0131 557 3332

✉ myelomauk@myeloma.org.uk

👉 myeloma.org.uk



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