



# National Cancer Patient Experience Survey 2018

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Clinical Nurse Specialists

August 2020



## 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 4966 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	10.6

**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.

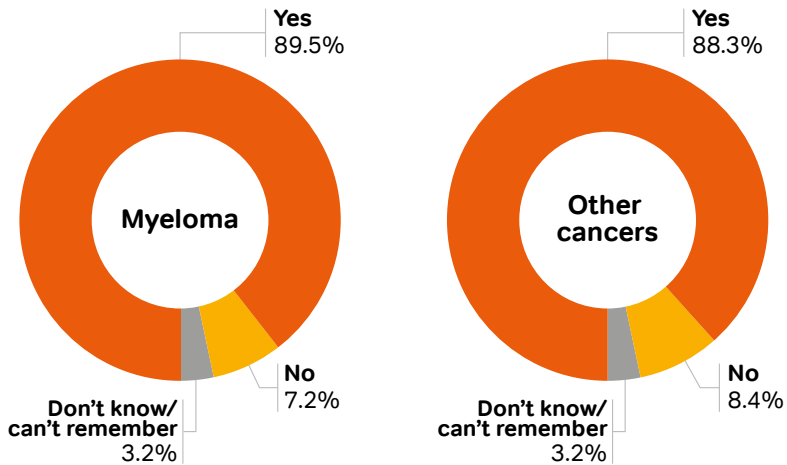
<sup>2</sup> NCPES suppresses results for categories where there are a small number of respondents to minimise the risk of individuals being identified.

## Clinical Nurse Specialists

This section summarises the results about access to, and use of, clinical nurse specialist (CNS) services.

### Were you given the name of a CNS who would support you through your treatment?

Nine out of ten myeloma patients were given the name of a CNS to support them through their treatment (Figure 1). A small proportion of myeloma patients were unsure if they had been given the name of a CNS which is similar to other cancers in general. Accounting for differences in age, sex, and ethnicity, **Myeloma patients are more likely to have been given the name of a CNS who would support them through their treatment compared to other cancers.**



**Figure 1.** Percentage of myeloma and other cancer patients who were given the name of a CNS who would support them through their treatment.<sup>1</sup>

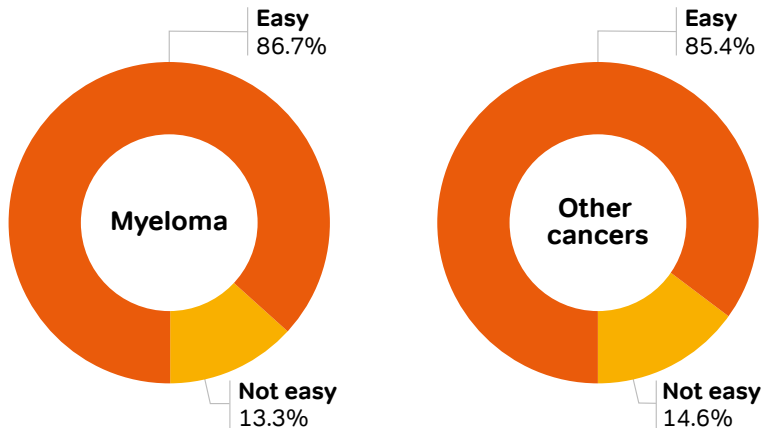
<sup>1</sup> Totals may not sum to 100% exactly due to rounding.

Myeloma UK is pleased to see that most myeloma patients are being given the name of a CNS who can support them through their treatment.

## How easy or difficult has it been to contact your CNS?

Of those who had been given the name of a CNS, 94.9% of myeloma patients had contacted their CNS compared to 88.8% of patients with other cancers in general.

Of those myeloma patients who had reached out to their CNS, the majority had a positive experience, finding it easy to contact their CNS (Figure 2). After accounting for differences in age, sex, and ethnicity, **myeloma patients found it as easy as patients of other cancers to contact their CNS.**



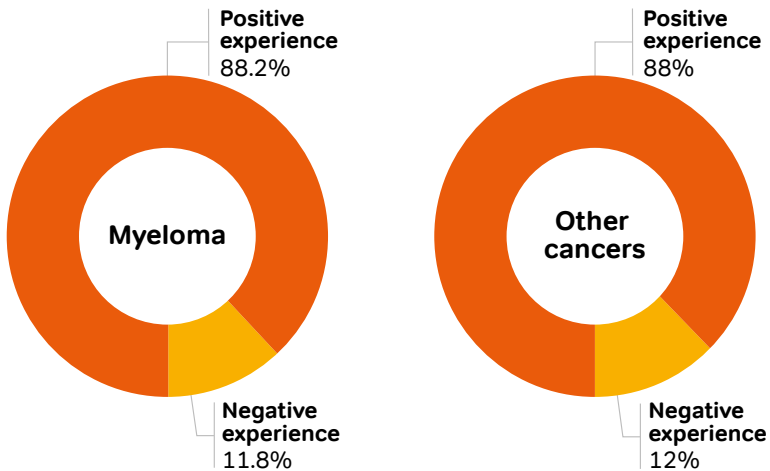
**Figure 2.** Percentage of myeloma and other cancer patients who found it easy to contact their CNS.

The majority of myeloma patients who are given the name of a CNS make use of this service. Myeloma UK is glad that the majority of myeloma patients find it easy to contact their CNS.

## When you had important questions to ask your CNS, how often have you got answers you could understand?

Of those who had been given the name of a CNS, 90.4% of myeloma patients had asked their CNS questions compared to just 85.4 of patients with other cancers in general.

**The majority of myeloma patients are receiving answers that they can understand which is similar to other cancers (Figure 3).**



**Figure 3.** Percentage of myeloma and other cancer patients who had a positive or negative experience of understanding answers from their CNS.

Myeloma UK recognizes the importance of clinical nurse specialists in the myeloma care pathway and we are glad to see that this service is being utilised by many myeloma patients. We are also happy that myeloma patients are not disadvantaged compared to other cancers in CNS care.

## Impact of demographic characteristics on patient experience with CNS care

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

Age	Given the name of a CNS		Contacting a CNS has been easy		Got understandable answers all or most of the time	
	Myeloma	Other cancers	Myeloma	Other cancers	Myeloma	Other cancers
<b>16-54</b>	93.2	90.2	89.0	82.7	86.9	85.1
<b>55-64</b>	91.6	90.2	86.8	84.0	86.1	86.9
<b>65-74</b>	90.1	89.5	86.0	85.9	88.5	89.0
<b>75-84</b>	87.9	85.7	87.2	87.8	89.0	89.5
<b>85+</b>	83.6	77.1	85.5	87.2	90.6	87.9
<b>Sex</b>						
<b>Male</b>	88.9	86.3	87.8	85.7	89.1	88.4
<b>Female</b>	90.4	90.0	85.1	85.2	86.8	87.6
<b>Ethnicity</b>						
<b>Black, Asian and minority ethnic</b>	90.9	88.1	85.0	81.0	77.4	82.1
<b>White</b>	89.4	88.4	87.2	85.8	89.6	88.7

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

## Age

Older myeloma patients were less likely to have been given the name of a CNS compared to younger myeloma patients. However, this finding is not unique to myeloma as older patients with cancer in general are also less likely to have been given the name of a CNS. For myeloma patients, the ease of contacting a CNS and getting understandable answers from a CNS is similar across age groups.

Myeloma UK is pleased that patients of all ages find it similarly easy to contact their CNS and get understandable answers from their CNS.



## Sex

Male and female myeloma patients were both as likely to have been given the name of a CNS. This is different to all cancers in general where men are less likely to have been given the name of a CNS than women. However, unlike other cancers in general, female myeloma patients are more likely to have difficulty in contacting their CNS compared to male myeloma patients. Similar to all cancers in general, female myeloma patients were less likely to have a positive experience in getting understandable answers from their CNS compared to men.

Myeloma UK is glad that there are no differences in the provision of a CNS across men and women. However, these results have shown that a slightly lower proportion of female myeloma patients are having a positive experience compared to men in utilising this service.

## Ethnicity

The likelihood of being given the name of a CNS and finding it easy to contact a CNS was similar for white, black and minority myeloma patients. However, similar to all cancers in general black and minority ethnic groups were less likely to get understandable answers all or most of the time compared to whites.

Myeloma UK is pleased that there are no differences across ethnic groups in being given the name of a CNS. However, we are frustrated to see ethnic disparities in CNS care with black and minority individuals far less likely to receive understandable answers to their questions compared to whites. Whilst we acknowledge that this is an inequality that is faced by cancer patients in general, the data suggests that the difference in care between whites and black and minorities is more pronounced for myeloma patients.

## Summary

- Nine out of ten myeloma patients were given the name of a clinical nurse specialist to support them through their treatment.
- A greater proportion of myeloma patients are reaching out to their CNS than other cancers in general. The majority of myeloma patients have a positive experience, finding it easy to contact their CNS which is similar to patients with other cancers.
- A greater proportion of myeloma patients are asking their CNS questions compared to other cancers. The majority of myeloma patients are receiving answers that they can understand which is similar to other cancers in general.

There were differences in CNS care across demographic groups:

- Black and minority myeloma patients are less likely to have understandable answers to their questions from a CNS compared to white myeloma patients.
- Similar to other cancers, older myeloma patients were less likely to have been given the name of a CNS than younger patients.
- A slightly lower proportion of female myeloma patients are having a positive experience compared to men in utilising CNS services.

## 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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