

Melanoma Patients Matter

Improving communication and support for patients during treatment and care

Executive summary

Bristol-Myers Squibb, the British Association of Skin Cancer Specialist Nurses (BASCSN), Melanoma Action and Support Scotland (MASScot), Melanoma Focus and Melanoma UK have come together to find out how patients are being involved in decisions about their care and treatment. The *Melanoma Patients Matter* project has been initiated and funded by Bristol-Myers Squibb, while the patient and professional group representatives have provided their experience and expertise in shaping the project and this resulting report.

This report summarises the results of a patient survey, which sought the views of a sample of patients with stage three or stage four melanoma across the UK, and five interviews with melanoma patients.

We found that:

- Only half of patients feel they completely understood their diagnosis and the nature of their illness, as explained by their doctor or Clinical Nurse Specialist (CNS)¹
- Nine in ten patients feel they have been involved in discussions about their treatment and care, to somewhat varying extents, though have often wanted to be involved more than they actually have been^{2,3}
- Only half of patients have found the information provided on treatment options to be 'completely' sufficient to make an informed choice⁴

- Two thirds of patients feel they have been able to have conversations about their priorities and expectations for treatment with their healthcare professionals.⁵

When these conversations have been happening, 79 percent of the time it has been the healthcare professional proactively initiating the discussion⁶ and 85 percent of patients feel they have been well listened to and that the discussion has then been acted upon⁷

- Nine in ten patients have been given the name of a CNS to support them during treatment,⁸ and nine in ten patients have found it relatively easy to contact their CNS.⁹ However, the extent to which patients have found their CNS is able to support them varies significantly, with a quarter of patients feeling that they have not received much support¹⁰

- Two thirds of patients have not been given a personalised care plan¹¹ and, of those who have been, 20 percent of these patients report not having been involved in its creation¹²
- 90 percent of patients who have received a care plan feel this has been a useful resource¹³

This report contains a series of recommendations for improvements to care and treatment, which we hope will lead to a gold standard of care being available for all melanoma patients across the UK.

Introduction

The NHS is committed to patients being at the heart of everything it does, and specifically ensuring patients are at the centre of any and all decisions made about their health.^{14,15} A diagnosis of melanoma often significantly changes a person's life, so it is important that patients are informed, supported and empowered to make decisions that are right for them and give them the best opportunity to lead the life they want. Actively involving patients in their own care, treatment and support can lead to improved outcomes and experiences.¹⁶

Less than a decade ago, treatment options for patients with advanced melanoma were limited, with chemotherapy the main treatment for many patients.¹⁷ In recent years, new treatments have become available for patients with advanced and metastatic melanoma – the first to be approved in several decades.¹⁷ The NHS has been relatively quick to adopt these,¹⁷ and now that there is a larger range of options available, it is important that all patients are provided with the information and support they need to make informed choices about which treatment would be best for them. This report is intended to explore how much this is happening in practice.

About this report

Bristol-Myers Squibb, the British Association of Skin Cancer Specialist Nurses (BASCSN), Melanoma Action and Support Scotland (MASScot), Melanoma Focus and Melanoma UK have come together to find out how patients are being involved in decisions about their care and treatment.

This report summarises the results of a patient survey, which sought the views of a sample of patients with stage three or stage four melanoma across the UK. We would like to thank all patients who took part in the survey and shared their experiences of living with melanoma. Informed by the survey findings and existing standards of care in cancer, this report makes a series of recommendations for ensuring advanced melanoma patients are empowered with sufficient and appropriate information to be as involved as they want to be in all decisions about their treatment, care and support.

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Melanoma key statistics



Melanoma is the UK's **fifth most common cancer**¹⁸



15,914
people were **diagnosed with melanoma across the UK** in 2015

1,366
people in Scotland²⁰

407
people in Northern Ireland²²

13,357
people in England¹⁹

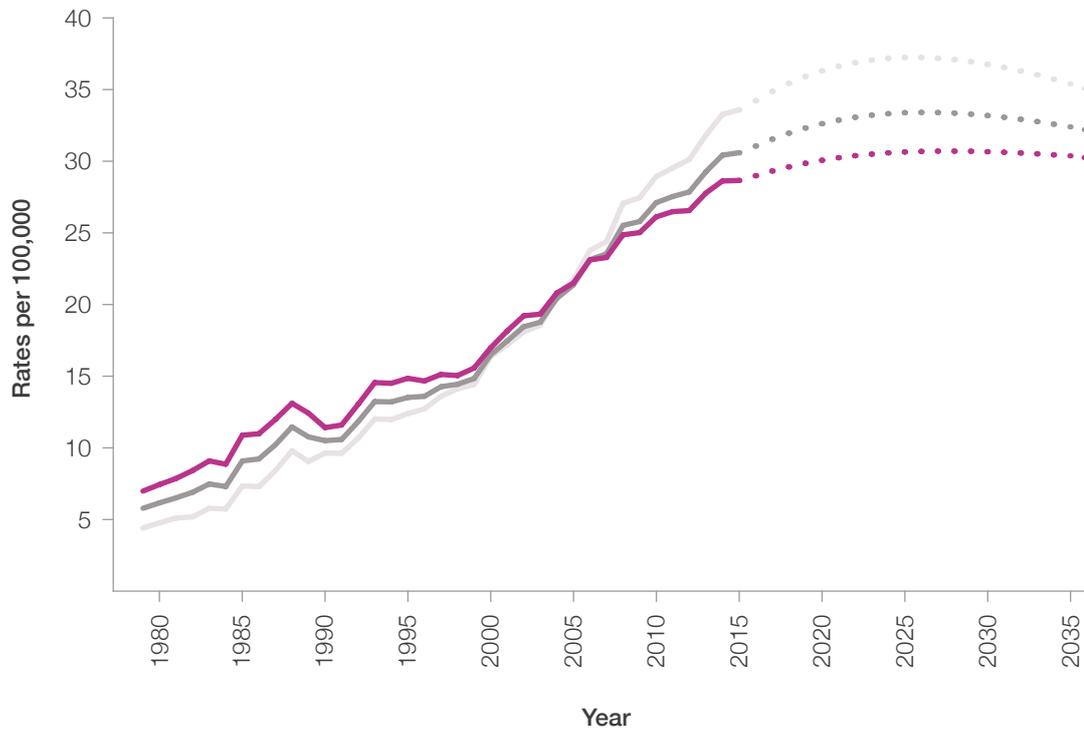


In the last decade alone, incidences of melanoma have **increased by 50 percent in the UK**, and it is projected to continue to rise¹⁸

784
people in Wales²¹

Melanoma Skin Cancer, Observed and projected age-standardised incidence rates, UK, 1979-2035²³

- Female ASR (observed/projected)
- Male ASR (observed/projected)
- Persons ASR (observed/projected)



Methodology

The Melanoma Patients Matter survey was developed in partnership with Bristol-Myers Squibb, the British Association of Skin Cancer Specialist Nurses (BASCSN), Melanoma Action and Support Scotland (MASScot), Melanoma Focus and Melanoma UK. Patients were informed of the survey by the patient group partners, via email and a notice on some patient group websites. The anonymous survey was live for a five-week period in September-October 2018.

The survey was hosted online and open to patients with stage three or stage four melanoma who are resident in the UK. In total, 104 patients responded to the survey. Although the results are not representative of the melanoma patient population as a whole, they do provide an important indication of the real life experiences of patients in the UK.

In addition to the patient survey, telephone interviews were conducted with five patients to provide some further insights into the experiences of individuals. Given the small number of patients interviewed, none of the conclusions in the report are based solely on information gathered through these interviews, and this information is presented as quotations throughout the report where it supports trends identified in the patient survey.

It should be noted that information obtained through the patient survey and patient interviews is subject to the respondent’s memory. This may mean that the information provided through the survey and interviews was incomplete or is skewed towards particular elements of care and treatment which are memorable. For example, side effects or discussions with particular professionals instead of more routine elements of their care.

Information, support and shared decision making

Shared decision making happens when health professionals and patients work together to arrive at decisions about their care and treatment based on the options available, clinical evidence and consideration of the patient's preferences.^{24,25}

This is particularly important in cancer care where there is an increasing number of treatment options, which can often involve relatively complicated decisions balancing the risks and benefits of treatment for each individual.²⁶ Therefore, it is crucial that patients are central to these decisions, and that their individual priorities and needs are taken into consideration.

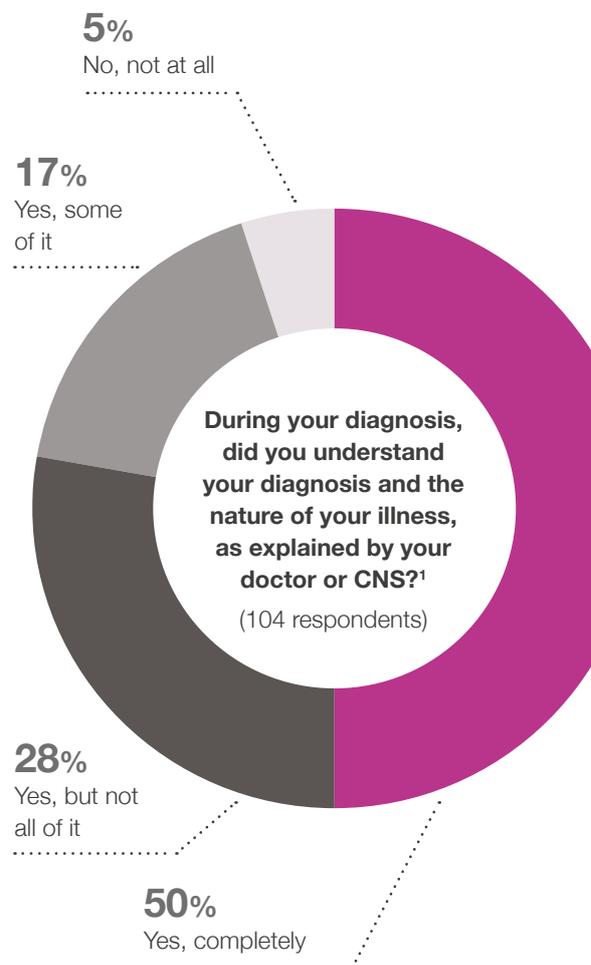
Our findings Information and support

Only half of the respondents to our survey felt they completely understood their diagnosis and the nature of their illness, as explained by their doctor or CNS.¹ A cancer diagnosis can be an overwhelming experience, so patients need access to the information and support that can help them understand what is happening and what to expect in the days and weeks following their diagnosis.

It is important that patients receive sufficient information to feel empowered to make an informed choice about the treatment and care that is right for them. The National Institute for Health and Care Excellence (NICE) provides guidance for healthcare professionals that considers communication and support as a core priority. It recommends written information be made available to all patients that is suitable to their diagnosis, treatment and associated needs.²⁷

No, not at all

Quote from a Stage 3 Melanoma patient when asked if they were given information about the stage of their cancer at diagnosis



I've never felt at
all that I missed
any information, that
they were not telling
me what I should know,
never, never felt like that

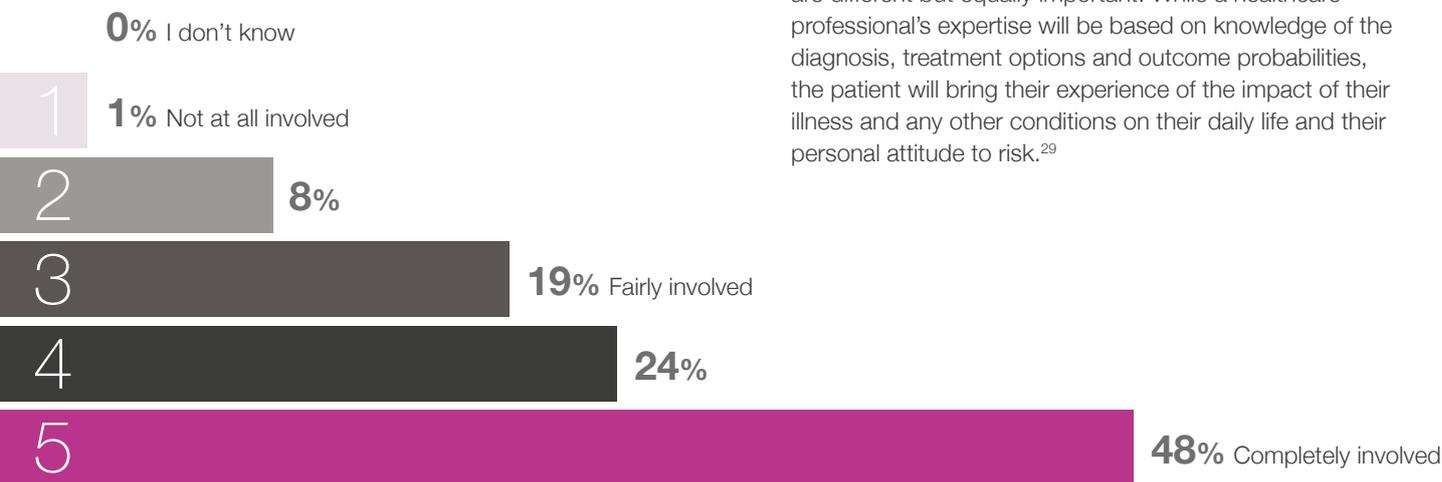
There's a group called Melanomamates, which is a group of melanoma patients... and it's absolutely amazing

Quote from a Stage 3 Melanoma patient



How involved do you feel you have been in decisions about your treatment and care?²

(104 respondents)



Sources of information

Understandably, patients' main sources of information during their diagnosis, treatment and follow up are typically their healthcare professionals, namely their doctor and/or their CNS.²⁸ In addition, four in ten patients told us that websites and other online sources are a main information source for them.²⁸ It is, therefore, key that healthcare professionals proactively suggest reputable online patient forums and patient group websites to their patients, such as MASScot, for patients in Scotland, and Melanoma Focus and Melanoma UK for patients elsewhere in the UK.

During your diagnosis, treatment and follow-up, what have been your main sources of information?²⁸

(Respondents were able to select more than one option)

	Specialist/Oncologist	78%
	CNS	57%
	Online/Website(s)	42%
	Other patients	32%
	GP	6%

Shared decision making

Central to the premise of shared decision making is that the expertise of healthcare professionals and patients are different but equally important. While a healthcare professional's expertise will be based on knowledge of the diagnosis, treatment options and outcome probabilities, the patient will bring their experience of the impact of their illness and any other conditions on their daily life and their personal attitude to risk.²⁹

I felt very involved

because [the oncologist] told me exactly what would happen with the immunotherapy and the outcomes, so then I could make a choice of what way I wanted to do it, and my choice is to go for the immunotherapy. It was my decision

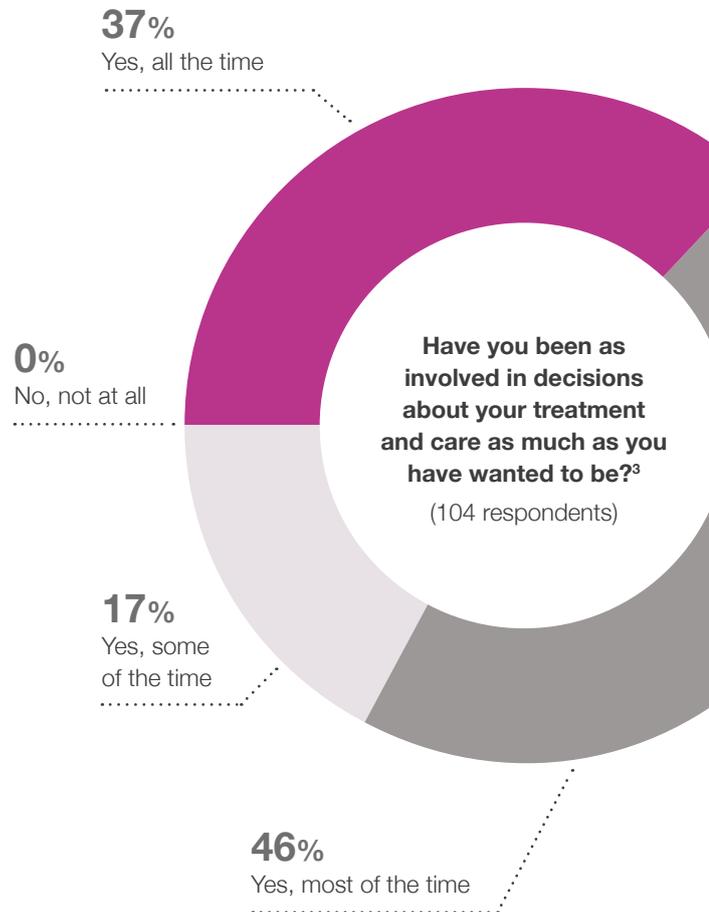
Quote from a Stage 3 Melanoma patient

We asked patients how involved they felt they had been in decisions made about their treatment and care. Nine in ten patients reported having been involved in these decisions to some extent,² though we also found that patients have often wanted to be more involved than they actually were.³ Given how significant these decisions are, it is crucial to ensure patients are always involved as much as they want to be, and it is clear that more must be done to ensure this is the case.

The way that they communicated the information to you was

pretty easy for you to understand

Quote from a Stage 4 Melanoma patient
on the information being easy to understand



Our recommendations

- At diagnosis, patients must be made aware of their rights and empowered by their healthcare professionals to be as involved as they want to be in any and all decisions relating to their treatment and care, and understand they are able to ask questions about any element of their care
- Clear, accessible information and support about a patient's diagnosis and all treatment options, must be provided as early as possible in a language and format appropriate for each patient to enable them to make informed decisions about their treatment and care
- Healthcare professionals must be equipped and willing to proactively provide information to patients about the physical and psychological effects of treatment and be able to sign-post patients to services and organisation where they can receive additional support

Knowing all options
available to me.

Understanding

all risks and the

advantages. Taking my

family into consideration

Quote from a Stage 3 Melanoma patient

Survey response to the question 'what were your top three priorities when having to make decisions about your treatment and care?'¹³²

Treatment options

As advanced melanoma patients may now have more than one treatment option, it is especially important that they are empowered to make the decision that is right for them by being provided with information about all of their options.

Our findings

We asked patients whether they felt their doctor had made them aware of all treatment options, and 76 percent told us they had been.³⁰ It may be that for some of the other patients, they were not eligible for some treatments and their doctor therefore will not have discussed these other options. However, it is nonetheless important that patients feel they are aware of all options and why they may not currently be suitable for them.

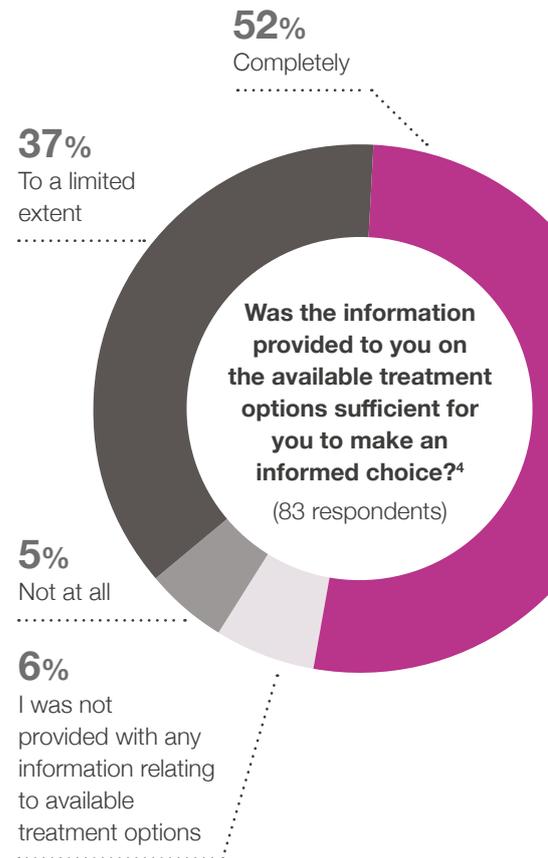
We asked patients if the information on treatment options was sufficient for them to make an informed choice. Of patients who had more than one treatment option available to them, only half told us that this information was 'completely' sufficient.⁴ A third of patients found the information to be sufficient 'to a limited extent', whilst the few remaining patients told us the information was 'not at all' sufficient or that they had not been provided with information.⁴ While 86 percent of patients told us that they felt able to ask their doctor, or another healthcare professional, any questions they had about the treatment options available to them,³¹ it is critical that patients have confidence that they have been given all of the information they need.

None...

I had the wide excision and the sentinel lymph node removed. And chatting to the surgeon [sic] he did say that whatever results come back, we will then discuss adjuvant therapy. But that has not been discussed with me

Quote from a Stage 3 Melanoma patient

when asked what information their doctor gave them about treatment options after diagnosis

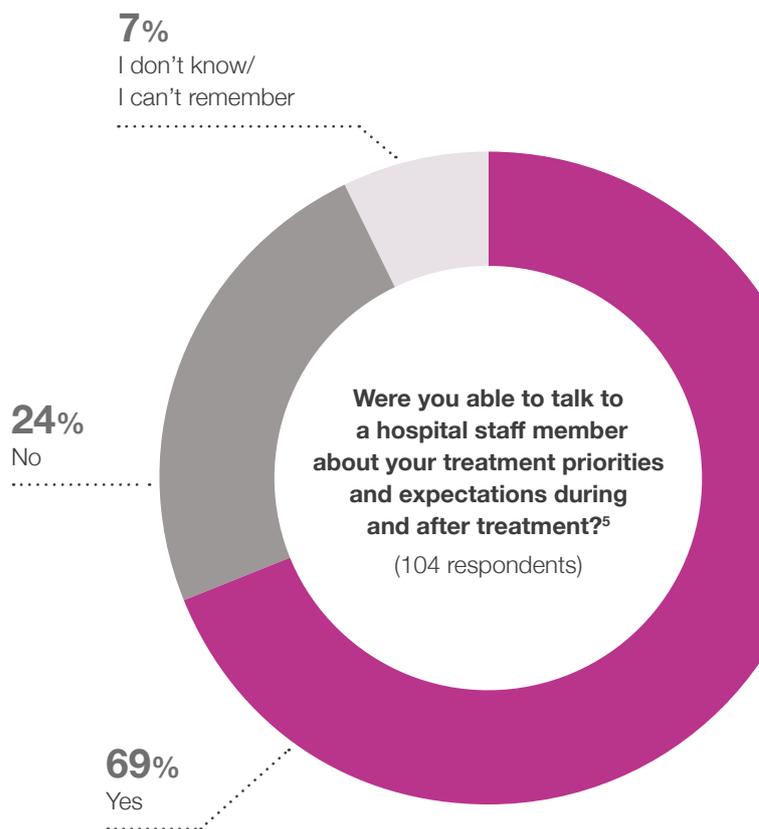


Did your doctor make you aware of all treatment options³⁰

(104 respondents)

✓	Yes	76%
✗	No	16%
?	I'm not sure	8%

As well as speaking to hospital staff about the treatment options, it is also important patients can have conversations about their personal priorities and expectations of treatment. Melanoma affects people of all ages and backgrounds, and priorities and expectations will be different for each patient. As such, healthcare professionals need to be able to help patients identify these when such decisions are being made. 69 percent of patients told us that they were able to have a conversation about their treatment priorities and expectations,⁵ and 79 percent of these patients said that it was a member of hospital staff who initiated the conversation.⁶

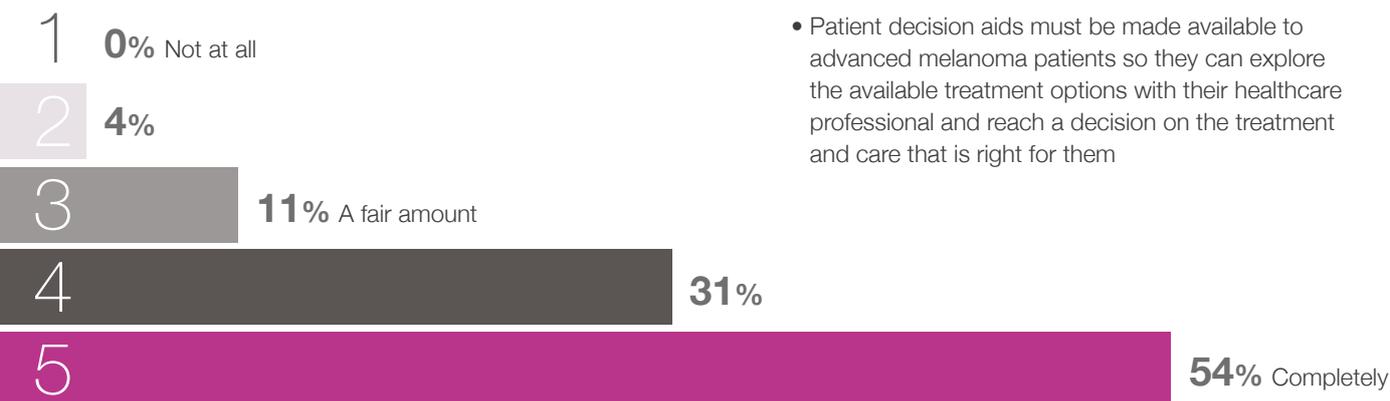


I didn't make any decisions,

I was told by my specialist what was going to happen

Quote from a Stage 3 Melanoma patient
Survey response to the question 'what were your top three priorities when having to make decisions about your treatment and care?'¹³²

How much were your treatment priorities and expectations listened to and acted upon by the doctors and nurses treating you?⁷
(72 respondents)



85 percent of patients having these discussions with their team of healthcare professionals found that they were listened to and that the discussion was then acted upon,⁷ which highlights the importance healthcare professionals proactively initiating these discussions with their patients.

Recommendations

- Healthcare professionals including surgeons, oncologists, dermatologists and CNSs need to have the time and opportunity to keep up to date with the latest treatments available for patients with melanoma
- In line with the principles of advanced communication skills training completed by healthcare professionals supporting cancer patients, all healthcare professionals should be having open and honest conversations with patients about the potential risks and benefits of the treatment options available, and how these may affect their day-to-day lives
- Patient decision aids must be made available to advanced melanoma patients so they can explore the available treatment options with their healthcare professional and reach a decision on the treatment and care that is right for them

I never really fully
understood what I
was told about the surgery
I was having. I did not even
know what questions to ask

Quote from a Stage 3 Melanoma patient

Survey response to the question 'what were your top three priorities when having to make decisions about your treatment and care?'³²



They [CNS] listen
to me, and they take
on board what I have
to say. I think I've got
really good support

Quote from a Stage 3 Melanoma patient

Clinical Nurse Specialists (CNSs)

Patients diagnosed with melanoma often require information and support beyond the clinical information they will receive from their doctor, and the support of CNSs is critical to this. The skin cancer quality standard from NICE and the clinical guideline from the Scottish Intercollegiate Guidelines Network (SIGN) make it clear that all patients with melanoma should have access to a named CNS.^{33, 34}

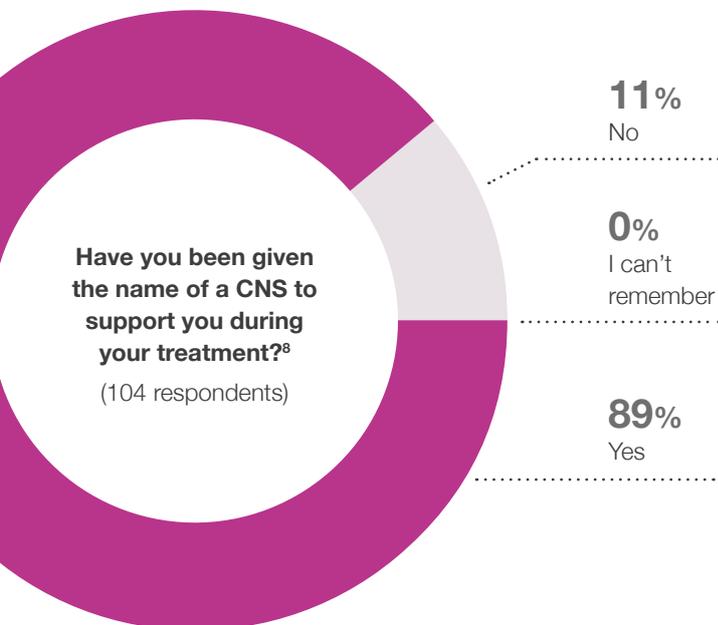
CNSs provide specialist support, guidance and advice on a range of clinical, emotional and practical issues during treatment, care and follow-up.^{33,35} Some CNSs may have developed their roles further and are able to diagnose, conduct physical examinations and prescribe treatments. CNSs also act as the patient’s advocate at MDT meetings, where a patient’s treatment and care is discussed, ensuring their interests are front and centre.

Our findings

Nine in ten melanoma patients responding to our survey told us they had been given the name of a CNS to support them during treatment,⁸ comparable to the findings of the most recent National Cancer Patient Experience Survey (NCPES).³⁶ This is also similar to NCPES findings for all cancer patients, and it is reassuring that melanoma is not an outlier.³⁶

As the treatment landscape in melanoma continues to develop, patients are likely to require more support from their CNS in helping them decide on the treatment and care that is right for them. While the specialist cancer nursing workforce is growing overall, there were only 194 CNSs for melanoma in 2017, making up five percent of the specialist cancer nurse posts.³⁷ While melanoma is the fifth most common cancer in the UK,¹⁸ its CNS workforce is the fourth lowest of all cancer specialties and capacity in certain areas of the UK may be stretched.³⁷ With melanoma incidence projected to increase further,³⁸ so too will the need for more CNSs to support these patients.

Notwithstanding substantial workforce pressures, nine in ten patients told us it has been relatively easy to contact their CNS.⁹ As other results from our survey tell us, CNSs are second only to a patient’s specialist/oncologist as the leading information source for patients,²⁸ it is reassuring that most patients are able to contact their CNS with relative ease.



I suppose that would be my cancer nurse

Quote from a Stage 3 Melanoma patient
on their primary source of information during diagnosis, treatment, and follow-up

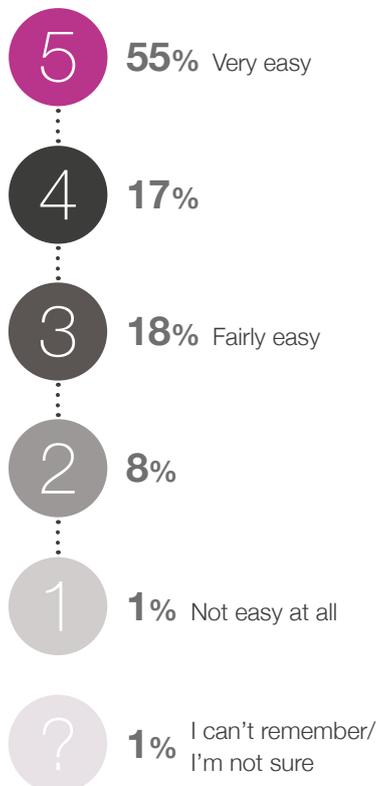
Very easy.

The three times I have rung her about different things, she has answered the phone immediately

Quote from a Stage 4 Melanoma patient on how easy it is to contact their CNS

On a scale of 1 to 5, how easy has it been to contact your CNS?⁹

(93 respondents)



However, while most patients have been assigned a named CNS and found them easy to contact, the support CNSs have been able to provide appears more varied. Although three quarters of patients said they felt well supported by their CNS in making treatment and care decisions, a quarter felt they did not receive much support.¹⁰ Because the melanoma CNS workforce is small in comparison to the prevalence of the disease, the mounting workload of CNSs may be leading to varying levels of support.

Our recommendations

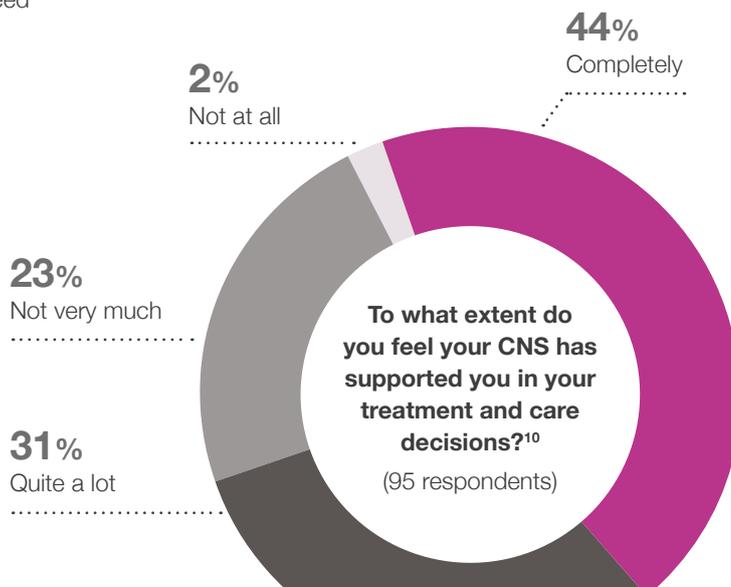
- Patients must be introduced to their CNS at diagnosis and be provided with written information that provides the contact details of their CNS, an overview of how their CNS can support them during their treatment and care, how they can book time in with their CNS, and who they should contact during periods of absence
- While maintaining ad hoc contact, it must be ensured that all patients have time booked with their CNS after every clinical meeting and other key points in their care to have quality discussions about care, treatment options and any further support they may need

- There must be a focused effort to expand the melanoma CNS workforce across the UK to ensure that all patients have access to a named CNS, irrespective of where they live and where they receive treatment

My cancer nurse would've been. She was invaluable.

She [was] responding to emails and text messages... if I was awake through the night, she would respond as soon as her shift kind of began. So yeah, she was my go-to

Quote from a Stage 3 Melanoma patient on who would be their go-to person for questions



Care plans

Cancer can, and often does, affect many areas of a patient's life. All treatment and care received by melanoma patients should reflect their individual needs and preferences and there should be opportunity to discuss the individual patient's expectations and priorities during treatment.

To ensure their needs and preferences are met, patients should have the opportunity to work with their CNS to create a personalised care plan. This should set out in detail the patient's programme of treatment, including how and where they will receive treatment and the frequency of this, alongside any personal circumstances that the patient wants to be considered by the wider team when arranging their treatment and care.

It is important that patients are involved in developing their care plan, that they understand the plans for their treatment and care, and recognise that the plan is used to ensure their individual needs and priorities are met. This document can then be shared with other members of a patient's treatment team to help inform their care. Usually at MDT meetings, the patient's CNS can ensure the plan is being referred to and use it to coordinate any additional support that the patient may need. Patients also receive a copy of their care plan, which can be a helpful reference document with information about their treatment, and can also be a document they refer to and use to feedback to their treatment team on any adjustments needed.

I haven't got a copy of the care plan, no...

he's never offered one and I've never asked for one

Quote from a Stage 4 Melanoma patient

The questions relating to care plans were only asked of patients who reported living in England, Wales or Northern Ireland, as care plans are not used in the same way in Scotland.

Our findings

Disappointingly, only a third of patients responding to our survey said they had been given a personalised care plan, with over half of patients saying they had not and 14 percent unable to remember.¹¹ Broadly, these findings correlate with those of the most recent NCPES results.³⁶

Over two thirds of patients who had a care plan told us they were involved in creating their care plan, but one in five (21 percent) said they had not been involved at all.¹² This highlights that, even where care plans exist, there is more to do to ensure that patients are fully involved in their development.



Yes, absolutely

Quote from a Stage 3 Melanoma patient on whether they would have liked to receive a care plan

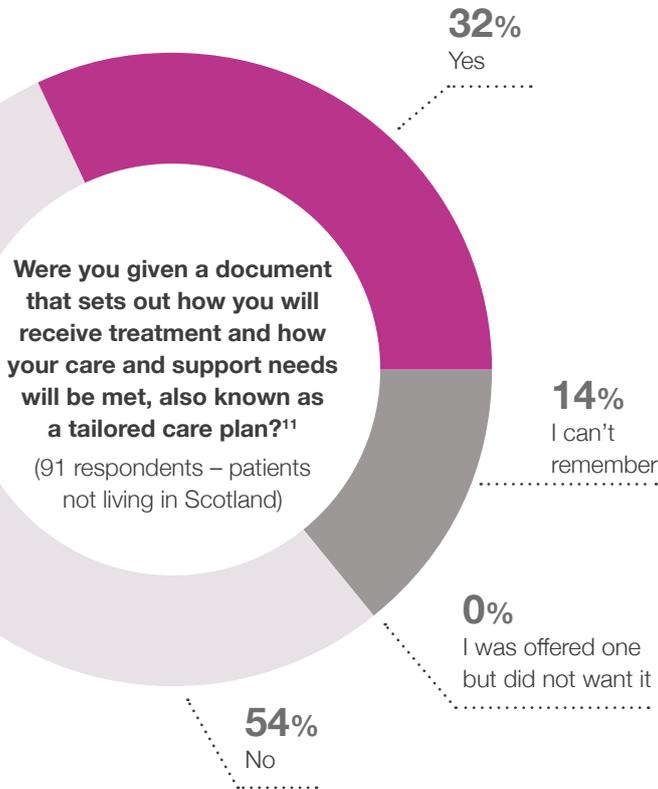
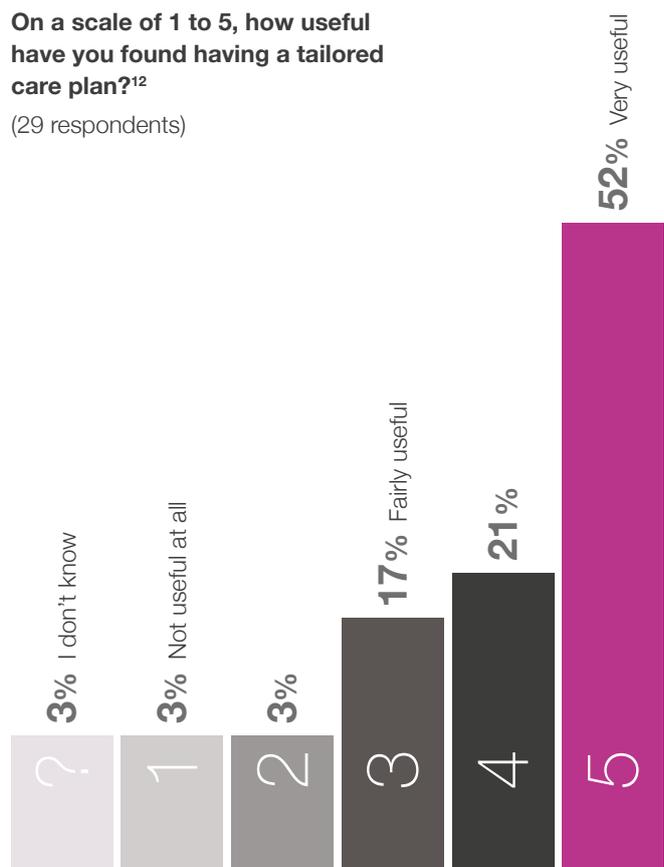
90 percent of patients who received a care plan have found it to be a useful resource,¹³ underlining how important they are. Significant progress is needed if NHS England is to meet its commitment of ensuring every cancer patient has a care plan by 2021, as set out in the recently published *NHS Long Term Plan*.³⁹ This also highlights the need for the NHS in Scotland to consider whether care plans would be of benefit to patients there, given the value patients elsewhere in the UK place on this resource.

Our recommendations

- NICE Guideline 14, 'Melanoma: assessment and management', should be refreshed to include a clear recommendation that a care plan is developed for, and shared with, all patients diagnosed with melanoma
- NHS England should ensure melanoma is an early adopter for the standardised roll out of care plans in cancer care
- NHS Scotland should consider introducing the concept of a personalised care plan to support melanoma patients' input, understanding and expectations of their individual treatment and care

On a scale of 1 to 5, how useful have you found having a tailored care plan?¹²

(29 respondents)



Were you given a document that sets out how you will receive treatment and how your care and support needs will be met, also known as a tailored care plan?¹¹

(91 respondents – patients not living in Scotland)

On a scale of 1 to 5, how involved were you in helping to create your tailored care plan?¹²

(29 respondents)

I don't know	0%
1. Not at all involved	21%
2.	3%
3. Fairly involved	7%
4.	28%
5. Completely involved	41%

Regular monitoring
by a team who care
about me. Easy access
to the team who would answer
queries with haste. Future
plans discussed regularly

Quote from a Stage 3 Melanoma patient

Survey response to the question, 'What were your top three priorities when having to make decisions about your treatment and care?'¹³²

Conclusion

Every patient's experience of melanoma is unique, and consequently their treatment and care should be tailored to meet their individual needs. The survey and interviews we carried out highlight both areas of good practice and areas for improvement in the treatment and care of melanoma patients.

While the concept of shared decision making is well established across the NHS and has considerable policy support,^{14,40} our survey found that melanoma patients' experience of this is varied. Patients must be empowered to make decisions on what treatment is right for them. This is vital for patients to have the best opportunity to lead the life they want, and for them to be at the centre of all decisions relating to their treatment and care. It is also crucial they are sufficiently informed and supported to make these decisions with their doctor and are confident in articulating what matters most to them.

To ensure that all patients with melanoma have the opportunity to be involved in their treatment and care, throughout this report we have made a series of recommendations focused on improving the experiences of patients with melanoma. BASCSN, Bristol-Myers Squibb, MASScot, Melanoma Focus and Melanoma UK are committed to taking these asks to policymakers in the UK to help achieve a gold standard of melanoma care across the UK.

Summary of recommendations

Information, support and shared decision making

- At diagnosis, patients must be made aware of their rights and empowered by their healthcare professionals to be as involved as they want to be in any and all decisions relating to their treatment and care, and understand they are able to ask questions about any element of their care
- Clear, accessible information and support about a patient's diagnosis and all treatment options, must be provided as early as possible in a language and format appropriate for each patient to enable them to make informed decisions about their treatment and care
- Healthcare professionals must be equipped and willing to proactively provide information to patients about the physical and psychological effects of treatment and be able to sign-post patients to services and organisation where they can receive additional support

Treatment options

- Healthcare professionals including surgeons, oncologists, dermatologists and CNSs need to have the time and opportunity to keep up to date with the latest treatments available for patients with melanoma

- In line with the principles of advanced communication skills training completed by healthcare professionals supporting cancer patients, all healthcare professionals should be having open and honest conversations with patients about the potential risks and benefits of the treatment options available, and how these may affect their day-to-day lives
- Patient decision aids must be made available to advanced melanoma patients so they can explore the available treatment options with their healthcare professional and reach a decision on the treatment and care that is right for them

CNSs

- Patients must be introduced to their CNS at diagnosis and be provided with written information that provides the contact details of their CNS, an overview of how their CNS can support them during their treatment and care, how they can book time in with their CNS, and who they should contact during periods of absence
- While maintaining ad hoc contact, it must be ensured that all patients have time booked with their CNS after every clinical meeting and other key points in their care to have quality discussions about care, treatment options and any further support they may need

- There must be a focused effort to expand the melanoma CNS workforce across the UK to ensure that all patients have access to a named CNS, irrespective of where they live and where they receive treatment

Care plans

- NICE Guideline 14, 'Melanoma: assessment and management', should be refreshed to include a clear recommendation that a care plan is developed for, and shared with, all patients diagnosed with melanoma
- NHS England should ensure melanoma is an early adopter for the standardised roll out of care plans in cancer care
- NHS Scotland should consider introducing the concept of a personalised care plan to support melanoma patients' input, understanding and expectations of their individual treatment and care

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I needed their [doctor's]
expert opinion on what
would be the right route
for me... Then I made
my decision on what
I wanted to do