



# Talking about melanoma matters

Improving communication, improving care

In recent years, discussions between healthcare professionals and melanoma patients have changed. The first new treatment options for several decades have become available for stage three and four melanoma, offering some patients better outcomes than they would have likely received just ten years ago.<sup>1</sup> As a result of these developments, patients now have more choices to make about their treatment and care. These choices can be complex and it is important that patients have all the information and support they need to be able to make fully informed decisions.

To support improvements in the conversations that take place at the point of referral, diagnosis, treatment and living beyond melanoma, Bristol-Myers Squibb has worked with the British Association of Skin Cancer Specialist Nurses (BASCSN), Melanoma Focus and Melanoma UK to set out some guiding principles for communicating well.

These have been largely informed by the experiences of over 100 patients, who responded to a survey conducted for the *Melanoma Patients Matter* project, on the information and support provided to them by their healthcare professionals from referral and diagnosis through to receiving treatment. BASCSN, Melanoma Focus and Melanoma UK have also made contributions to these principles, based on their day-to-day experiences of supporting melanoma patients.



## GP appointment and referral

If a patient is concerned about any changes to their skin, they can discuss this with their GP. If the GP has concerns that these changes may be linked to melanoma, they should refer their patient to a dermatologist and explain the reason for the referral to their patient, broaching the possibility of melanoma. The GP will consult guidelines to decide if their patient needs an urgent referral to a dermatologist.

If, as a patient, you do not agree with your GP's decision not to refer you, you can ask them to explain their decision. If you still have concerns, you can ask to be referred to another practice GP who specialises in skin cancer, if your GP has not already suggested this. Not all GPs have experience of skin cancer and they may seek an opinion from another practice GP who has this experience to determine whether their patient should be referred.

### Was it explained to you why you were being referred?

"It felt as though they perhaps didn't want you to know that they suspected melanoma. They didn't want you focusing on that."



### As a patient, you should consider:

- **Asking your GP to explain why they have decided to refer you to a dermatologist**, and what you can expect from the upcoming appointment. Also, if your GP has decided not to refer you, you should ask them to explain the reason
- **If still concerned following a decision not to refer you to a dermatologist**, asking for a second opinion from another GP within the practice with experience of skin cancer



### Patients say they want their healthcare professionals to:

- **Fully explain the decision whether or not to refer them to a dermatologist, and what this might entail.** If a patient is unhappy with a decision not to refer, they want the opportunity to seek a second opinion from another GP in the practice. If they are referred, patients want their secondary care healthcare professional to ensure they fully understand the reason for their referral from what has already been explained by their GP



## Diagnosis

Only half of melanoma patients responding to the survey felt they completely understood their diagnosis and the nature of their illness [at the point of diagnosis], as explained by their clinician or clinical nurse specialist (CNS).<sup>2</sup> This means many patients leave their appointment without understanding what exactly melanoma is and what their diagnosis means for them on a day-to-day basis. While a diagnosis can be an overwhelming experience, it is important that patients have access to information and support that can help them understand what melanoma is, what is happening and what to expect in the days and weeks following their diagnosis.



### As a patient, you should consider:

- **Asking for anything which you do not understand fully to be explained more clearly**
- **Asking your clinician to provide you with written information, such as leaflets or links to helpful patient group websites,** to strengthen your understanding of what you have been told
- **Contacting your CNS to discuss your diagnosis** and raising questions that may come to you in the days and weeks after diagnosis, which is very common. If you have not received contact details for your CNS, you should ask your clinician for these



### Patients say they want their healthcare professionals to:

- **Communicate all information thoroughly and in plain English,** assuming that as a patient they have no prior knowledge of melanoma
- **Explain the next steps,** reassuring them as a patient that there is a plan in place, and helping them to understand what to expect in the days, weeks and months ahead – from surgery, treatment decisions and disruptions to day-to-day life
- **Provide written information** to supplement what is communicated verbally. Patients want to be signposted to reputable sources of information, such as that provided by melanoma patient groups
- **Remember that as a patient they may have difficulty taking in lots of information when they are first told they have melanoma.** While it is important to explain all of the options available to them, it is also important to offer a further appointment and make sure that they have contact details for their team of healthcare professionals, including their CNS
- **Outline to them everyone who will be involved in their care,** so they know who to contact about different aspects of their care. Importantly, patients want to be introduced to, and provided with the contact information for, their CNS
- **Have plans in place for one of the healthcare professional team to follow up with them in the days following diagnosis,** to discuss any questions they may have when they have thought more about their diagnosis

### At your initial diagnosis, what were you told about your diagnosis and the nature of your illness?

“Not very much... All they told me was that it was melanoma, and that I would need to go in and have further surgery.”



### How appropriate to your needs was the information you received at that time of diagnosis?

“I think it was quite poor.”

### At your initial diagnosis, what were you told about your diagnosis and the nature of your illness?

“Well, I received plenty of information. My mind was a bit of a blur, but I have to say they were very thorough. The oncologist, Clinical Nurse Specialist and dermatologist were all there to answer my questions.”





## Treatment

Deciding what treatment to have, as well as where and when that treatment takes place, will have a substantial impact on a patient's life. Therefore, it is vital that patients are empowered to play as much of a role as they would like to in making decisions around the treatment they will receive. While a clinician will provide medical expertise based on the diagnosis, patients will bring their experience of the impact of the illness on their daily lives and their personal attitude to risk.<sup>3</sup>

### What did you think was stopping you becoming more involved?

"Making the wrong decision myself possibly when I'm no expert."



### As a patient, you should consider:

- **Asking why a treatment has been suggested or recommended for you by your clinician**, as well as what it will entail and what you can expect as a result of this treatment. You should also remember that you can change your mind on treatment at any point, and you also have the right to refuse treatment if you feel that is right for you
- **Contacting your CNS or other healthcare professional to discuss the treatment you are taking**, as well as any side effects which they may be able to help you better manage

### Patients say they want their healthcare professionals to:

- **Discuss treatment options with them as early as possible**, so they can understand the choices available to them and are able to take time to assess their personal priorities and preferences for treatment
- **Provide them with written information on all treatment options discussed**, covering what the treatment is, how it is provided and the side effects associated with the treatment
- **Ensure that as a patient they have an opportunity to discuss their treatment options with their CNS**

### Who do you feel made the decisions about your treatment and care?

"I was just told what needed to be done and, to a degree, I understand that – they are the experts. But, afterwards I found out that I could have made a decision on where I would have the treatment, perhaps a hospital where my family could easily visit."





## Living beyond melanoma

With the introduction of innovations in treatment, around nine in ten melanoma patients can now expect to survive their cancer beyond ten years,<sup>4</sup> so there is reason to be positive when discussing what happens after treatment has ended and life beyond melanoma.

After treatment, patients may have the same or greater support needs than they did when receiving treatment. Patients may need to be signposted by their healthcare professionals to organisations that can support them as they resume a 'normal' life. As melanoma has a high chance of returning, it is important that patients also understand how to monitor their condition and who to contact if they have any concerns between follow-up appointments.



### As a patient, you should consider:

- **Discussing with your doctor and CNS what your *personal* preferences are for monitoring and follow up.** You may prefer to make regular check-ins for peace of mind, or you may prefer less contact limited to the normal clinical reviews
- **Contacting your CNS following the end of treatment.** It is understood that you may still need support in the weeks, months and years once treatment has ended and you should contact them as needed. Also, if you are concerned your melanoma may have returned, your CNS will be able to make arrangements to get you the care and treatment you need



### Patients say they want their healthcare professionals to:

- **Ensure that as a patient they understand how to monitor for any recurrence of melanoma and who to contact if they have any concerns**
- **Encourage them as a patient to be positive and have hope for the life ahead of them beyond melanoma, and speak to them about living a longer and better life**

## References

- <sup>1</sup> The Melanoma Taskforce, *The New Melanoma Treatment Environment*, 2017. Available at: <https://www.melanomauk.org.uk/wp-content/uploads/2017/03/The-New-Melanoma-Treatment-Environment-Melanoma-Taskforce-Report-FINALv3.pdf>. Last accessed: May 2019
- <sup>2</sup> Bristol-Myers Squibb, Melanoma Patients Matter: Improving communication and support for patients during treatment and care, 2019. Available at: <http://bascsn.com/melanoma-patients-matter/>; <https://melanomafocus.com/information-portal/support-patients-matter/>; <https://www.melanomauk.org.uk/news/melanoma-patients-matter>. Last accessed: May 2019
- <sup>3</sup> Coulter, A. and Collins, A., *Making shared decision-making a reality: No decision about me, without me*, 2011. Available at: [https://www.kingsfund.org.uk/sites/default/files/Making-shared-decision-making-a-reality-paper-Angela-Coulter-Alf-Collins-July-2011\\_0.pdf](https://www.kingsfund.org.uk/sites/default/files/Making-shared-decision-making-a-reality-paper-Angela-Coulter-Alf-Collins-July-2011_0.pdf). Last accessed: May 2019
- <sup>4</sup> Cancer Research UK, *Melanoma skin cancer statistics*, 2019. Available at: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/melanoma-skin-cancer#heading=Two>. Last accessed: May 2019



### Further information and support

**Melanoma Focus**  
melanomafocus.com  
0808 801 0777

**Melanoma UK**  
melanomauk.org.uk  
0808 171 2455