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What matters most? A national listening project for people affected by melanoma and skin cancer

Summary of findings for Melanoma UK

10 February 2026

melanoma UK

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Introduction

Melanoma UK asked Thiscovery to carry out this listening project to learn what people affected by melanoma and skin cancer need most. This summary shows what we learned from a national listening project.

Between November and December 2025, 136 people across the UK shared their experiences through our online survey, including 85 people with lived experience of skin cancer diagnosis, 37 family members and carers, and 14 members of the wider public. People were invited to complete the survey through the Thiscovery secure online platform. The platform helps people get involved in research to make health and care better in the UK.

The findings show both good and difficult parts of people's experiences with melanoma and other types of skin cancer. They identify clear priorities for how Melanoma UK and the broader healthcare system can better support people affected by melanoma and skin cancer.

What we learned

Most people were diagnosed with melanoma, but many were unsure what type: Of the 85 people with lived experience, 83% had been diagnosed with melanoma, whilst others had basal cell carcinoma (24%) or squamous cell carcinoma (8%) with some experiencing more than one skin cancer type. When the 70 people diagnosed with melanoma were asked what type, 59% were not sure or didn't know. Among the 28 family members and carers of someone with melanoma, 68% were not sure or didn't know what type their loved one had.

Getting diagnosed was different for everyone: People had very different experiences. Some were sent quickly to see a specialist doctor and felt their worries were taken seriously from the start. Others had to wait longer or were told at first that their symptoms were not serious. Some people had to push hard to get the care they needed on time.

Not everyone felt involved in choosing their treatment: Of the 85 people with lived experience, 44% felt completely involved in decisions about their treatment and 14% felt involved quite a bit. However, 15% felt somewhat involved, 12% felt only a little involved, and 10% felt not at all involved.

Most people made changes to protect themselves after diagnosis: Of the 85 people with lived experience, 93% reported checking their skin more frequently, 92% sought shade more often, and 90% wore more protective clothing. Only 1% reported making no changes.

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People wanted practical information, not just medical facts: Many people told us they wanted practical help with things like wound care, dealing with unwanted effects from treatment, and managing everyday life after being diagnosed.

Many family members and carers got no support for themselves: Of the 34 people who were asked what support they had received for themselves as a supporter or carer, 36% said they had received none, of which 18% didn't know what support was available, while another 18% said they didn't need support. Only 9% had accessed emotional or psychological support.

People had different ideas about what Melanoma UK should focus on, but prevention campaigns were most popular: Of the 122 people who were asked what Melanoma UK should focus on, 56% of people selected public awareness and prevention campaigns, 48% selected better information for newly diagnosed people, and 43% selected funding research into prevention and treatment.

Many people would engage with Melanoma UK on social media: We showed people an example Melanoma UK social media post. 66% of 121 people said they would stop and read it.

Of the 122 responses to the social media usage question, Facebook was the most common (66%,) followed by Instagram (53%).

Participant demographics

Of the 120 people who provided demographic information, most were aged 45-64 (58%), with smaller proportions aged 25-44 (18%), 65-74 (18%), 75 or over (3%), and 16-24 (1%).

Most people were female (80%) and 19% were male. No one was non-binary or chose to describe their gender differently. One person (1%) preferred not to say.

Almost all people were White (97%). Very small numbers were Mixed or multiple ethnic groups (2%) or Black, British Black, Caribbean or African (1%). No one was Asian or British Asian, or chose other ethnic group. 1% preferred not to say. This means the findings may not show what people from other backgrounds experience.

What questions were asked?

The survey used both tick-box questions and questions where people could write their own answers. This helped us gather numbers and personal stories. We designed the survey with help from Melanoma UK staff, medical advisors and people living with melanoma and skin cancer.

People answered different questions depending on their connection to melanoma and other skin cancer. The survey asked about:

- **Diagnosis and treatment experiences** - pathways to diagnosis, types of treatment received, involvement in treatment decisions, and life after treatment
- **Getting information and support -** where people found information, what was helpful, what information was missing, and experiences of support from professionals and other people affected by melanoma and other types of skin cancer
- **Supporting others** - experiences of family members and carers, their information needs, and how they felt supported
- **Prevention and awareness** - what people know about risks, how they protect themselves from the sun, and checking skin for changes
- **Melanoma UK priorities** - what people wanted the charity to focus on, how they prefer to hear from Melanoma UK, and whether they donate

This project was commissioned by Melanoma UK and part funded by Merck Pharmaceuticals.

How the research will help Melanoma UK's work

Melanoma UK will use what they learned from this project to guide their work going forward. The findings showed that what people want matches what the charity is already doing, which means they can keep focusing on the same important areas including raising awareness, providing information, and funding research. They don't need to change direction completely, but they will work on doing these things even better. The charity plans to create an action plan based on what people told them.

The survey results support the goals of the new National Cancer Plan, especially around prevention, diagnosis and supporting people after cancer. This means they can work alongside national goals to help give people what they're asking for. The survey results have given the charity confidence that they're on the right track and shown them where to focus their efforts to best support people affected by melanoma and other skin cancer.

About Thiscovery

Thiscovery works to support better health and care across the UK. They listen to the people who use, work in and care about health services - including patients, NHS staff and the public. Thiscovery helps organisations understand what these people need and what matters to them. They turn these insights into useful information that helps create better products, policies and services. Their work helps charities, hospitals, researchers and other organisations make decisions based on what people really want and need.

This means health and care services can improve in ways that make a real difference to people's lives.

To find out more please visit www.thiscovery.org or email programmes@thiscovery.org