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Patient research priorities in melanoma: a national qualitative interview study

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Abstract

Background Outcomes for advanced melanoma have improved following the advent of immunotherapy and targeted therapy. This heralds a need for reconsideration of future research agendas. Patients can – and are keen to – help identify and prioritize research topics to ensure future research benefits patients. No previous peer-reviewed research has reported patient research priorities for melanoma.

Objectives To determine the prioritized research topics of patients with melanoma in England.

Methods Patients aged ≥ 18 years, diagnosed with melanoma in the past 10 years, were recruited across England by skin cancer charities. Preinterview questionnaires obtained demographic, tumour and treatment information. Semi-structured interviews were conducted where patients were asked what they thought were important topics to research in melanoma. Using a grounded theory approach, transcripts were analysed in an iterative process to identify themes for patient research priorities.

Results Twenty patients were individually interviewed from eight of nine English regions. Five key themes were identified: (1) 'Risk factors and prevention of melanoma' – patients voiced a desire for research into modifiable risk factors and public campaigns to prevent melanoma; (2) 'Diagnostic delay and misdiagnosis of melanoma' – patients felt diagnostic delays could be reduced through research to support nonspecialists and integrating technology such as teledermatology or artificial intelligence'; (3) 'Indications, outcomes, side-effects and interactions of treatments for melanoma' – novel treatments inspired patients to encourage future research into the indications, outcomes and side-effects of therapeutic options; (4) 'Optimizing follow-up for melanoma' – with increased survivorship, research to support the delivery of a personalized approach to follow-up was valued; and (5) 'Factors that influence survival from melanoma' – patients prioritized research to accurately predict recurrence and survival based on patient-specific factors.

Conclusions This is the first peer-reviewed study to report patient research priorities in melanoma. Many of the themes identified align with National Institute for Health and Care Excellence research recommendations. Additionally, novel themes were identified that provide a rationale to develop a James Lind Alliance Priority Setting Partnership for melanoma. If research addresses topics relevant to patients, decision-makers will be equipped to deliver services that meet patient needs.

Lay summary

Melanoma is a type of skin cancer. It is relatively common and can have a huge impact on a person's quality of life. In some cases, melanoma can result in death. Although there has been a lot of progress in developing new treatments, we do not know what people with melanoma think is most important to research. Therefore, we need to ask people what they think researchers should be looking at, so that we can make sure that future research benefit patients.

This study was carried out in England. It aimed to find out what the important unanswered research priorities are of people with melanoma. To identify the research priorities, we interviewed 20 adults with melanoma. Patients provided insight into their experiences with melanoma and used these experiences to help us to identify future research priorities. We found five main areas that people with melanoma care about: understanding what causes melanoma, how to diagnose it, how to treat it, how to follow up with patients after treatment and how to improve survival rates.

This was the first study to ask patients with melanoma what research they think is most important to them. These study findings could help researchers determine which topics should be focused on in the future, to make sure their work is useful to patients.

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What is already known about this topic?

- The incidence of melanoma is increasing and with high morbidity and associated mortality, melanoma is likely to be a growing burden on global healthcare resources.
- A key aspect of good research is to focus on topics of importance to patients; funders attach increasing importance to patient research priorities.
- There is a lack of qualitative, patient-focused research in melanoma, and no research has been published on patient research priorities in melanoma.

What does this study add?

- In-depth analysis of real-world patient experiences highlighted five fundamental patient research priorities in melanoma; risk factors, diagnosis, treatment, follow-up and survival.
- Patients prioritized research into ways they could reduce their risk and improve survival from melanoma and how best this information could be shared with the wider population.
- New treatments and increased survivorship have driven patients to seek further improvements in treatment and personalized follow-up for melanoma.

What are the clinical implications of this work?

- This study encourages funding calls and research to address topics relevant to patients, equipping decision-makers with data to deliver services that meet patient needs.
- Key themes were identified, providing a rationale and groundwork to develop a James Lind Alliance Priority Setting Partnership for melanoma.

'Patient-centred research' was highlighted as a key theme in a 2021 UK government report entitled 'The Future of UK Clinical Research Delivery'.[1] This emphasis represents progress in research funding and development, and ensures that patients' priorities are of paramount importance. Advanced melanoma management has undergone significant transformation following the development of targeted treatments/immunotherapies.[2] This led to the reconsideration of research agendas. The National Institute for Health and Care Excellence (NICE) recommendations for research focus on biomarkers, surgical margins and disease surveillance.[3] Funders are prioritizing patient and public involvement, with a shift toward patient-focused research and outcomes.[4,5] Clinicians provide key insights into future research directions; however, patients can support clinicians to inform these directions through the provision of patient perspectives. For example, highlighting the impact on quality of life from scarring related to the diagnosis and treatment of melanoma has provided valuable information to help improve management strategies. If research addresses questions relevant to patients, decision makers will be equipped to deliver services that meet patient needs.[6,7] In 2023, a Priority Setting Partnership (PSP) study was published for skin cancer surgery; however, the identified research priorities lacked specificity for melanoma and were limited to priorities related to surgery.[8] No patient research priority studies in melanoma have been published worldwide in peer-reviewed journals.[9] The objective of this study was to identify and prioritize the unanswered research topics of patients with melanoma.

Patients and methods

Study design

This was a qualitative semi-structured interview study of patients with melanoma across England conducted in line with the Standards for Reporting Qualitative Research (SRQR) checklist (Appendix S1; see Supporting Information).

Patient/public involvement

A patient representative (J.R.) was a co-author and inputted on recruitment and patient-facing documentation, and developed the thematic scheme.

Sampling and recruitment

Eligible participants self-reported a diagnosis of cutaneous melanoma within 10 years, were resident in England and were aged ≥ 18 years. Purposive sampling was done using demographic data obtained from preinterview questionnaires. Participants were recruited by The Melanoma Focus Trial Finder (https://melanomafocus.org/melanoma-trialfinder/) and by flyers distributed at patient conferences and support groups, and by newsletters. Participants who expressed interest in taking part received a participant information sheet/consent form (Appendices S2, S3; see Supporting Information). Written and verbal consent was gained, and participants received a £50 voucher. Sample size was determined by 'meaning saturation', achieved by

Table 1 Participant characteristics

Patient ID	Sex	Age group (years)	Ethnicity	Disability	Region	Site	Stage	Subtype	Treatment
P1	M	65–74	White	No	West Midlands	Scalp/neck	4	Superficial spreading	Surgery, immunotherapy
P2	F	25–34	White	No	South West	Face	Unknown	Unknown	Surgery, immunotherapy
P3	F	55–64	White	No	North West	Lower limb	1	Superficial spreading	Surgery
P4	F	75–84	White	Yes	South East	Trunk	4	Nodular	Surgery, targeted therapy, immunotherapy
P5	F	55–64	White	No	East Midlands	Lower limb	3	Unknown	Surgery
P6	M	65–74	White	No	East of England	Upper limb	1	Superficial spreading	Surgery
P7	F	35–44	White	Yes	Yorkshire and the Humber	Upper limb	4	Superficial spreading	Surgery, targeted therapy, immunotherapy
P8	F	45–54	White	No	East Midlands	Upper limb	1	Superficial spreading	Surgery
P9	F	65–74	White	No	West Midlands	Trunk	3	Nodular	Surgery
P10	F	45–54	White	No	East of England	Lower limb	3	Nodular	Surgery, targeted therapy, chemotherapy
P11	F	65–74	White	No	South West	Lower limb	3	Amelanotic	Surgery, immunotherapy
P12	F	55–64	White	Yes	South West	Trunk	4	Nodular	Surgery, immunotherapy, radiotherapy
P13	F	45–54	White	Yes	London	Lower limb	1	Superficial spreading	Surgery
P14	F	45–54	White	Yes	East of England	Trunk	4	Unknown	Surgery, immunotherapy, radiotherapy
P15	F	65–74	White	No	East Midlands	Lower limb	3	Superficial spreading	Surgery, immunotherapy
P16	F	55–64	White	No	East Midlands	Upper limb	2	Superficial spreading	Surgery
P17	F	45–54	White	No	East of England	Trunk	4	Nodular	Surgery, immunotherapy, radiotherapy
P18	M	65–74	White	No	West Midlands	Trunk	4	Unknown	Immunotherapy
P19	F	65–74	White	No	Yorkshire and the Humber	Lower limb	3	Superficial spreading	Surgery, immunotherapy
P20	F	65–74	White	No	South West	Scalp/neck	3	Unknown	Surgery, targeted therapy

F, female; M, male.

collecting rich data within the analysis and new interviews adding little new material.[10]

Interviews

Participants completed preinterview questionnaires on demographics, tumour and treatment information, and answered screening questions to identify research priorities (Appendix S4; see Supporting Information). Interviews were conducted virtually by O.S. and K.M. from November 2023 to May 2024 using Zoom (https://www.zoom.com/). Details about the research group are provided in Appendix S5 (see Supporting Information).

The interview topic guide was informed by a patient representative, clinical/research experts and literature review (Appendix S6; see Supporting Information). The guide prompted participants to address three topics: what would be interesting/important areas to research in (i) melanoma overall, (ii) melanoma epidemiology/genetics/diagnosis and (iii) treatment/follow-up/recurrence/survival. Given the overlap between questions, interviewers adopted a flexible approach and did not ask every question in the guide, to avoid repetition.

Data collection and analysis

Interviews were coded and analysed by K.M. and D.K. Data collection and analysis were undertaken concurrently. Interviews were audio- and video-recorded using Zoom. Interviews were transcribed verbatim and pseudonymized. Data and coding were managed using NVivo 14 (https://lumivero.com/products/nvivo/). Analysis was inductive, searching for themes in the data.[11–13] As suggested by Charmaz,[10] an exploratory grounded theory approach was used with several phases of coding. Through a continuous iterative process, codes were developed to build interpretation using constant comparison. In the final stage of coding, themes/subthemes of patient research priorities were defined and refined. The authors discussed the analysis in multidisciplinary discussions and the final thematic organization was agreed upon by all authors.

Techniques to enhance trustworthiness

Multiple methods triangulation was used with separate analyses of research priorities using preinterview questionnaire data and interview data.[14] Synthesized member checking

Table 2 Overview of themes on patient research priorities in melanoma

Theme	Subthemes	Categories
1. Risk factors and prevention of melanoma	Modifiable factors that influence the risk of melanoma and how to prevent melanoma	Sun-related risk factors Health-related risk factors
	Nonmodifiable factors that influence the risk of melanoma	Understanding genetic inheritance, syndromes and mutations Incidence trends by age group Risk by skin colour/ethnicity
	Improving patient and public education to prevent melanoma	Avoiding medical jargon Identifying and implementing effective ways to improve public knowledge of melanoma and ways to prevent it
2. Diagnostic delay and misdiagnosis of melanoma	Reducing the knowledge gap between dermatologists and nondermatologists	Education and support for nonspecialists Postcode lottery
	The causes and impact of diagnostic delay for melanoma	Miscommunication between primary and secondary care Long waiting lists COVID-19
	The role of technology in increasing diagnostic accuracy and reducing waiting lists	Artificial intelligence Teledermatology
	Accuracy of less invasive diagnostic methods for melanoma	Biopsy method Reflectance confocal microscopy Blood tests and genetic testing
	Indications and accuracy of SLNB for melanoma	Indications of SLNB Accuracy of SLNB
3. Indications, outcomes, side-effects and interactions of treatments for melanoma	Duration, indications, outcomes, side-effects and interactions of immunotherapy for melanoma	Indications for immunotherapy Optimal duration and long-term outcomes of immunotherapy Frequency and severity of side-effects from immunotherapy, including long-term side-effects Interactions of immunotherapy
	Duration, outcomes and side-effects of targeted therapy for melanoma	Optimal duration and long-term outcomes of targeted therapy Frequency and severity of side-effects from targeted therapy, including long-term side-effects
	Complications from surgery for melanoma	Preoperative education Prevention and management of scarring
	Effectiveness and safety of novel treatments in development for melanoma	Non-*BRAF* targeted therapy Melanoma cancer vaccines Tumour-infiltrating lymphocytes
4. Optimizing follow-up for melanoma	Effectiveness and availability of holistic support after a melanoma diagnosis	The role, impact and availability of different sources of support Palliative care Support for family members
	Duration and frequency of follow-up for melanoma	Optimal duration of follow-up Frequency of visits Likelihood of recurrence
	Effectiveness and availability of investigations to detect recurrences during follow-up	Teaching patients self-examination Scans and digital mole mapping Circulating tumour DNA and blood tests to detect recurrence
5. Factors that influence survival from melanoma	Modifiable lifestyle factors that influence survival from melanoma	Health-related survival factors Non-health-related survival factors
	Nonmodifiable risk factors that help patients come to terms with their melanoma experience	Survival by genetics, *BRAF* subtypes, non-*BRAF* mutations Survival by stage and subtype of melanoma
	Long-term survival from melanoma	Survival rates beyond 5–10 years

SLNB, sentinel lymph node biopsy.

was used where the themes/subthemes from the whole participant sample were returned to participants and participants engaged with and added to the interpreted data to confirm the credibility of results.[15]

Ethical considerations

A distress protocol was designed to provide a safe, consistent approach to distress during interviews (Appendix S7; see Supporting Information). There were concerns regarding fraudulent participation from six participants due to inconsistent or missing information on preinterview questionnaires, interview answers contradicting information obtained from preinterview questionnaires and aggressive, repeated requests for further financial reimbursement. Following legal advice and discussion with the multidisciplinary research team (including the ethics committee, patient representative, funder and sponsor), the research group successfully submitted amendments to the ethics committee to remove the monetary reimbursement and make video-recording mandatory. No further suspicious cases arose following these changes. Data from the six potentially fraudulent participants were excluded from the analysis. More details on the identification, prevention and management of suspected fraudulent participation have been described elsewhere.[16]

Results

Meaning saturation was achieved after 20 interviews. The mean interview duration was 45 min (range 28–57).

Participant characteristics are provided in Table 1. Participants were from eight of nine English regions, ranged in age from 25 to 84 years and 85% (n=17/20) were women. Mean age was not available.

Analysis resulted in 5 themes and 19 subthemes (Table 2). These are discussed below, from the patients' perspective. Additional illustrative quotes are provided in Table S1 (see Supporting Information).

Theme 1: Risk factors and prevention of melanoma

The first theme emphasized patients' need for research into risk factors and prevention of melanoma, which was divided into three subthemes.

Subtheme 1.1: Modifiable factors that influence the risk of melanoma and how to prevent melanoma

Participants valued research to develop evidence-based changes they could make to prevent melanoma. They felt this would empower them to take positive actions. The priority was on research exploring whether sun-related and lifestyle factors such as diet, vitamin D levels or co-prescriptions influence the risk of melanoma. They indicated the need to quantify sun-related risk factors and the impact that reducing sunscreen cost could have on use.

> *'I'm constantly asked was I a sun worshipper? I wasn't. I had one blistered sunburn as a child, I have always been careful…so, yeah, I think there's a lot of research that needs to be done' (Patient 7).*

Subtheme 1.2: Nonmodifiable factors that influence the risk of melanoma

Many patients expressed concerns they could have passed on the risk of melanoma to their children. Patients felt more research was required to identify genes that could be inherited. For somatic mutations – defined as mutations that occur after conception and are not inherited – patients were keen to understand what factors predispose to them. Patients highlighted the lack of data on melanoma risk in young people and minority ethnic groups as a focus for research.

> *'I just want research to explode the myth that it's just something that you face in old age' (Patient 11).*

Subtheme 1.3: Improving patient and public education to prevent melanoma

Participants expressed concern at the lack of public knowledge on melanoma risk factors and urged research to identify effective ways to promote sun safety awareness, including school education, social media and conferences. This was based on participants' general perception of the public's knowledge and their own knowledge prior to melanoma diagnosis. They were advocates for research to evaluate school education as this targets younger audiences.

> *'I don't believe that there is enough coverage in the public domain. Especially with the younger generations' (Patient 14).*

Theme 2: Diagnostic delay and misdiagnosis of melanoma

The second theme concerned research to mitigate diagnostic delays and misdiagnosis, and was divided into five subthemes.

Subtheme 2.1: Reducing the knowledge gap between dermatologists and nondermatologists

Although acknowledging nondermatologists were not specialists in melanoma, patients wanted more research to support nonspecialists to ameliorate misdiagnosis. They proposed the knowledge gap could be reduced with research to develop training courses or pathways where nonspecialists could seek specialist input. They hoped this could reduce what they saw as a 'postcode lottery' in health service and clinician competency.

> *'I don't know how much training general practitioners get…I know melanoma is on the rise. Maybe they need more training or more support' (Patient 15).*

Subtheme 2.2: The causes and impact of diagnostic delay for melanoma

Diagnostic delay caused frustration and nervousness for patients. COVID-19, miscommunication between primary and secondary care, and funding were suggested as the cause of delays. When patients looked online, they were unable to find information on the reasons for the delays and the potential impact of delays on mental health, quality of life and survival.

> *'I want to know if there are measures or studies assessing the effect of waiting time for results on patients…We are in a permanent state of waiting…It is that uncertainty that causes a lot of anxiety' (Patient 16).*

Subtheme 2.3: The role of technology in increasing diagnostic accuracy and reducing waiting lists

Technological innovation was thought of by patients as a neglected area that could provide solutions to waiting lists. Patients with experience of technological innovations described positive experiences and many were keen for research to explore teledermatology and artificial intelligence to improve diagnostic accuracy and reduce waiting lists.

> *'I have the SkinVision app and I think I highlighted one of my areas on that. Then I got an email telling me the dermatologist has looked at it and says that it needs to be looked at urgently' (Patient 14).*

Subtheme 2.4: Accuracy of less invasive diagnostic methods for melanoma

Although patients understood excisional biopsies were necessary, they resulted in high burden such as pain and scarring, and some patients ended up having many. Patients were keen for accurate but less invasive diagnostic options. Ideas included smaller biopsies, blood tests or reflectance confocal microscopy.

'It would be nice to have a needle test…Rather than having chunks chopped off all the time' (Patient 16).

Subtheme 2.5: Indications and accuracy of sentinel lymph node biopsy for melanoma

Some patients were unclear on whether sentinel lymph node biopsy (SLNB) was appropriate and wanted more evidence on the benefits to weigh against the risks such as lymphoedema. Patients felt uneasy about false-negative results given the implications this could have for access to systemic therapy.

'I was worried about getting a false negative [SLNB] and not getting the immunotherapy' (Patient 19).

Theme 3: Indications, outcomes, side-effects and interactions of treatments for melanoma

The third theme described treatments for melanoma as a research priority. Four subthemes were identified.

Subtheme 3.1 Duration, indications, outcomes, side-effects and interactions of immunotherapy for melanoma

Patients recalled clinicians struggling to decide between immunotherapy or targeted therapy. Some experienced anxiety on stopping immunotherapy and felt more research was needed into the optimal duration and long-term outcomes. Awareness and experiences of immunotherapy side-effects affected patients' decisions to start or continue immunotherapy, so research into the frequency, severity and long-term side-effects was welcomed. Patients mentioned that there was no advice regarding immunotherapy interacting with other medications they were prescribed.

'Do other drugs I take improve or decrease the effect of the cancer treatment [immunotherapy]?' (Patient 4).

Subtheme 3.2 Duration, outcomes and side-effects of targeted therapy for melanoma

Patients expressed that research into targeted therapy lagged behind immunotherapy and that more information on long-term outcomes, optimal duration and side-effects is required.

'As a melanoma patient, there doesn't appear to be a huge amount of information on targeted therapies' (Patient 17).

Subtheme 3.3: Complications from surgery for melanoma

Preoperative education was an area for research, with patients recalling clinicians being unable to answer questions regarding the frequency of side-effects with a surgical approach. Patients considered surgical scarring as a neglected area of research that affects quality of life, so clinicians should investigate methods to mitigate/treat scarring.

'What surgical repair provides the best outcome for cosmetics and less failure, for example graft or secondary intention or stitch material or finding out what type of skin you have before surgery and scar likeliness?' (Patient 2).

Subtheme 3.4: Effectiveness and safety of novel treatments in development for melanoma

Patients cited experiences where they enquired about non-BRAF targeted therapies, tumour-infiltrating lymphocytes (TILS) and cancer vaccines, but professionals stated there was not enough evidence on their effectiveness and safety.

'…I was just wondering whether there would be research into other mutations and into drugs targeted at those other mutations?' (Patient 15).

Theme 4: Optimizing follow-up for melanoma

The fourth theme identified patients wanted research to support effective follow-up. This was reflected in three subthemes.

Subtheme 4.1: Effectiveness and availability of holistic support after a melanoma diagnosis

Participants highlighted that holistic support services during melanoma follow-up, such as mental health, occupational health, charities and support groups, required improved implementation, but – once accessible – they had a profoundly positive impact on their lives and their families. They suspected the strain on health services reduced the availability of holistic support, and research demonstrating its usefulness could improve funding.

'…there was quite a long wait before I could access talking therapies. They were very good…I think there needs to be better holistic care' (Patient 13).

Subtheme 4.2 Duration and frequency of follow-up for melanoma

Patients felt abandonment once follow-up was completed, which was exacerbated by stories of late recurrences. Thus, patients asked for more long-term data on recurrence rates and patient-specific factors that influence recurrence. Conversely, patients appreciated that resources were limited and that indefinite follow-up was unrealistic, although some mentioned that patient-initiated follow-ups (where within a stated time window a patient can contact their health professional to arrange a follow-up if a specified patient concern arises) could resolve this.

'I can't tell you how many posts I read where people develop melanoma again once the checks stop. So, I think it would be quite helpful to know on what basis is NICE limiting the checks to 5 years…' (Patient 11).

Subtheme 4.3: Effectiveness and availability of investigations to detect recurrences during follow-up

Patients wanted research into education programmes to help them identify concerning moles. Although wanting autonomy, they advocated for investigations to identify recurrences accurately such as circulating tumour DNA/other blood tests. Patients discussed heterogeneity in the frequency, body parts and modality (positron emission tomography vs. computed tomography) of scans offered. Patients were frustrated by geographical variations in mole-mapping

availability and felt that research into its effectiveness for early detection could reduce disparities.

'I noticed that, through all the patients that I have spoken to, the scan cycle seems to differ depending on the NHS [National Health Service] trust you belong to. As a patient, that can cause a lot of anxiety…' (Patient 17).

Theme 5: Factors that influence survival from melanoma

The fifth theme identified research priorities surrounding survival, reflected in three subthemes.

Subtheme 5.1: Modifiable lifestyle factors that influence survival from melanoma

Patients were grateful that survival has improved due to new drugs but mentioned that there was limited advice on changes to lifestyle factors such as diet that could affect survival from melanoma. Many actively participated in online forums and were alarmed by the number of posts where variation in geographical and socioeconomic factors potentially influenced survival due to delays in being seen.

'I had two friends who had tumours…One of them read a book about changing your lifestyle, diet and supplements, etc. The friend of mine that survived her tumour changed to a healthier lifestyle' (Patient 12).

Subtheme 5.2: Nonmodifiable risk factors that help patients come to terms with their melanoma experience

Patients encouraged research to understand how gene mutations (*BRAF*/*NRAS*/other mutations), melanoma subtypes and stage at diagnosis are associated with survival. Patients felt that identifying the factors that influence survival, although not necessarily actionable, provides them with key prognostic information of value, because it helps them to come to terms with their melanoma experience.

'…I don't seem to have ever come across any survival statistics based on the type of melanoma, for example nodular vs. superficial spreading. It is important for patients to have an idea of what their chances are so they can come to terms with it' (Patient 10).

Subtheme 5.3: Long-term survival of melanoma

With many patients diagnosed with melanoma at a young age and increasing survivorship, patients highlighted an unmet need for better long-term survival data.

'There is 5-year [survival] data but not 10-year data' (Patient 20).

Discussion

As melanoma understanding and management progresses, it is vital to consider what patients think future research should focus on. This is the first peer-reviewed study to provide an in-depth qualitative account of patient research priorities in melanoma. The themes identified reflected the unique, rich and personal experiences of patients. Patients prioritized five themes: risk factors, diagnosis, treatment, follow-up and survival.

Patients desired more research into modifiable factors and public campaigns to prevent melanoma. From a patient perspective, discovery of new genes could inform risk and unlock targeted therapies. Patients voiced that diagnostic delays could be improved through research to support nonspecialists and integrating technology. The issue of overdiagnosis was not raised as a concern by participants. Improvements in systemic treatment inspired patients to encourage future research into the indications, outcomes and side-effects of established and novel therapeutics. With greater survivorship, research to support effective follow-up was important. Patients wished ongoing research to accurately predict recurrence and survival based on patient-specific factors.

A range of priority topics were recognized; however, in relation to clinical practice, guidelines and current research some topics may have already been or are being addressed. Many key priority areas identified aligned with those previously identified and explored. For example, the Australian State of the Nation report raised similar concerns and there may have been similar work done by other organizations.[17] It is common for patients living with a disease to seek information on treatment and prevention, and there is ongoing research into immunotherapy, targeted therapy, vaccines and TILS, with existing or pending guidelines in these areas.[3,18,19] Conversely, there is less research into how we can improve public education to prevent melanoma or the impact of lifestyle factors on risk and survival from melanoma.[9] Focusing on lesser explored research areas may be most useful to prioritize.

Although important, some priority topics may not be pragmatic. For example, without quality longitudinal data, it is challenging to reliably report the long-term survival of people with melanoma. Some participants' concerns were specific to UK healthcare, such as NHS delays or ambiguity regarding follow-up. In the UK, primary care physicians refer patients with suspected melanoma to dermatologists; thus, delays may occur in referral, being seen by a specialist or initiating management following diagnosis.[3] The severity of delays may vary depending on the region in which a patient lives. Current UK guidance recommends follow-up for 5 years for the majority of patients with accompanying scans; however, patients described local adherence to guidance varied across geographical regions.[3] Some priority topics may have been considered more important by patients, but it was beyond the scope of this work to rank the importance of each topic. The James Lind Alliance (JLA) PSP brings patients, carers and clinicians together to inform the 'top 10' research priorities within a disease.[4] This 'top 10' list is publicized widely to researchers/funders attracting funding calls.[9,20] No JLA PSP exists for melanoma: this study lays the groundwork for one.

The strength of this study was its rigorous qualitative methodology. Thematic analysis drew upon elements from grounded theory: multiple phases of coding, sampling until saturation and constant comparison. One-to-one interviews rather than focus groups were chosen to empower patients to answer using personal experiences.[21] A key challenge was to achieve diverse patient engagement, so the data were representative of the patient population. Patients more interested and educated in melanoma, or with late-stage diagnoses may have been more likely to participate. Conversely, patients may be unaware of the latest advances

in research and struggle to suggest future research priorities. Despite purposive sampling and multiple recruitment methods there was a lack of people younger than 25 years of age, male participants, people from minority ethnic groups and participants with early-stage disease. This may be explained by the lack of participant responses in these groups. Future research should attempt to better understand the research priorities in these groups.

In summary, in-depth interviews identified patient research priorities in melanoma that spanned a range of core topics. This provides a benchmark for researchers to ensure future research aligns with patient research priorities, which is imperative to improving the lives of patients with melanoma.

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Conflicts of interest

N.J.L. is a trustee of the British Association of Dermatologists. Paul Leighton is an Associate Editor for the Outcomes and Qualitative Research section of the *BJD*. The other authors declare no conflicts of interest.

Data availability

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Ethics statement

Ethical approval was approved through the Integrated Research Application System (23/NW/0276).

Patient consent

Written and verbal consent to participate was obtained from all patients.

Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's website.

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