Fiona Brady Foundation

Skin Cancer Survey

May 2026

Skin Cancer Patient Experience Survey 2026

Executive Overview

Introduction

Throughout May 2026, The Fiona Brady Foundation conducted an online survey to gather insight into the experiences of individuals and families affected by skin cancer across Northern Ireland.

The survey was created using Google Forms and promoted through the Foundation's social media channels. A total of 28 responses were received from people with direct or indirect experience of skin cancer, including patients, family members and carers.

The purpose of this survey was not to provide a statistically representative analysis of all skin cancer patients in Northern Ireland. Rather, it was designed to capture lived experiences, identify recurring themes, and provide a platform for individuals affected by skin cancer to share their perspectives on awareness, diagnosis, treatment, support services and cancer care.

Respondents were asked a series of questions covering:

- Skin cancer diagnosis and type
- Awareness and early detection
- Experiences of diagnosis and treatment
- Access to information and support
- Emotional and psychological wellbeing
- Family and carer support
- Barriers to care
- Perceptions of cancer services in Northern Ireland
- Priorities for improvement and policy change

Why This Matters

Skin cancer remains one of the most common forms of cancer in Northern Ireland, with incidence rates continuing to rise. Despite this, public awareness of warning signs, prevention and early detection remains inconsistent.

Early diagnosis significantly improves outcomes for many forms of skin cancer. Understanding patient experiences can help identify opportunities to improve awareness campaigns, reduce diagnostic delays, strengthen support services and ensure that patients and families receive the care they need throughout their cancer journey.

Behind every diagnosis is a person, a family and a story. The experiences shared through this survey provide valuable insight into the realities of living with skin cancer in Northern Ireland and highlight areas where meaningful improvements can be made.

Key Objectives

This survey was undertaken to:

- Better understand patient and family experiences of skin cancer care in Northern Ireland.
- Explore perceptions of public awareness and early detection initiatives.
- Identify barriers to diagnosis, treatment and support.
- Assess experiences of emotional, psychological and practical support.
- Gather recommendations directly from those affected by skin cancer.
- Inform policymakers, healthcare professionals and stakeholders about opportunities for improvement.

About The Fiona Brady Foundation

The Fiona Brady Foundation was established in memory of Fiona Brady, who died from metastatic melanoma in January 2024 at the age of 36.

The Foundation exists to raise awareness of skin cancer, promote earlier detection and encourage conversations that may ultimately save lives. Through education, advocacy and community engagement, the Foundation seeks to ensure that more people recognise the signs of skin cancer and feel empowered to seek medical advice when concerns arise.

This report represents the voices of those who generously shared their experiences in the hope that future patients and families may benefit from improved awareness, earlier diagnosis and stronger support throughout their cancer journey.

A Note on Interpretation

The findings presented within this report reflect the experiences and opinions of the survey participants and should be viewed as qualitative insight rather than a comprehensive population-level study.

While the sample size is relatively small, the themes identified offer valuable perspectives from people directly affected by skin cancer and provide important context for discussions around awareness, service provision and patient support across Northern Ireland.

Your Voice Can Help Shape Cancer Care in Northern Ireland Survey

Survey findings report: skin cancer experiences, awareness and support needs. May 2026

Based on 28 survey responses

Prepared for public release and to support discussions with healthcare professionals and politicians. Contact details supplied by respondents have been removed and are not reproduced in this report.

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Respondents described a system where awareness is too low, diagnosis and follow-up can feel slow or uncertain, and emotional, practical and family support is inconsistent. The clearest opportunities for improvement are earlier recognition, faster and more transparent pathways, better communication, and accessible support after diagnosis.

**Important limitation: this was a self-selecting survey and should not be presented as statistically representative of all skin cancer patients in Northern Ireland. It is, however, a valuable patient/public voice dataset for identifying priorities and lived-experience themes.*

Executive summary

Finding	Evidence from cleaned dataset
Public awareness is the strongest concern	22/26 respondents who answered **(84.6%)** said there is not enough visibility or public awareness around skin cancer warning signs and early detection.
Diagnosis experiences are mixed	13/28 respondents **(46.4%)** rated speed of diagnosis as Poor or Very Poor; 11/28 **(39.3%)** rated it Good or Very good.
Support services are not visible enough	14/28 **(50.0%)** were not aware of support services, charities or community resources; 9/28 **(32.1%)** were partially aware.
Psychological and emotional support is inconsistent	10/28 **(35.7%)** felt Not at all or Not enough emotionally supported; 25/28 **(89.3%)** said psychological/counselling support was unsure, difficult to access or not available.
Families and carers need greater attention	13/28 **(46.4%)** said family/carers did not receive enough support; 10/28 **(35.7%)** were unsure.

**Respondents were not required to answer all questions. Therefore, total number of responses to each question may differ.*

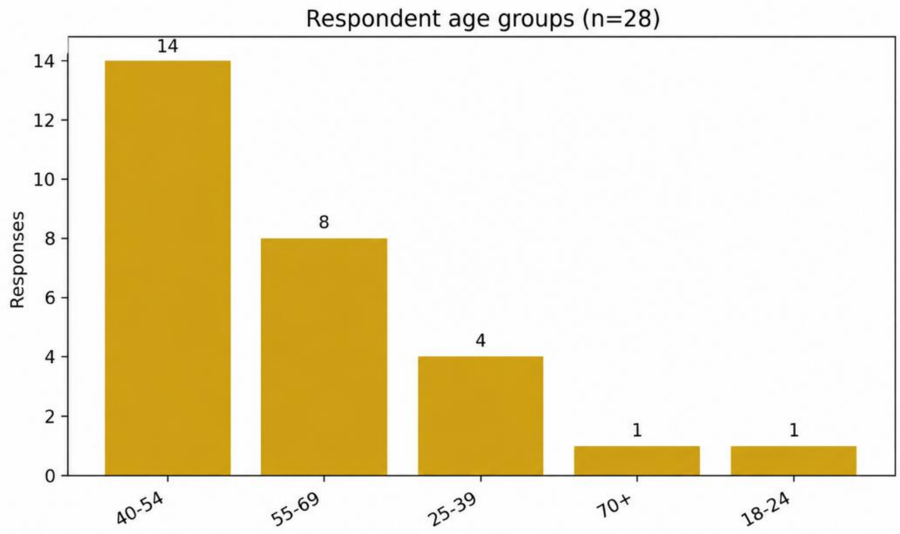
Overall, respondents described a need for earlier recognition, clearer referral routes, better communication while waiting for results or follow-up, and more visible emotional, peer and community support.

Respondent profile

The survey included 28 responses: 25 from people diagnosed with skin cancer, 2 from family members/carers and 1 from a bereaved family member.

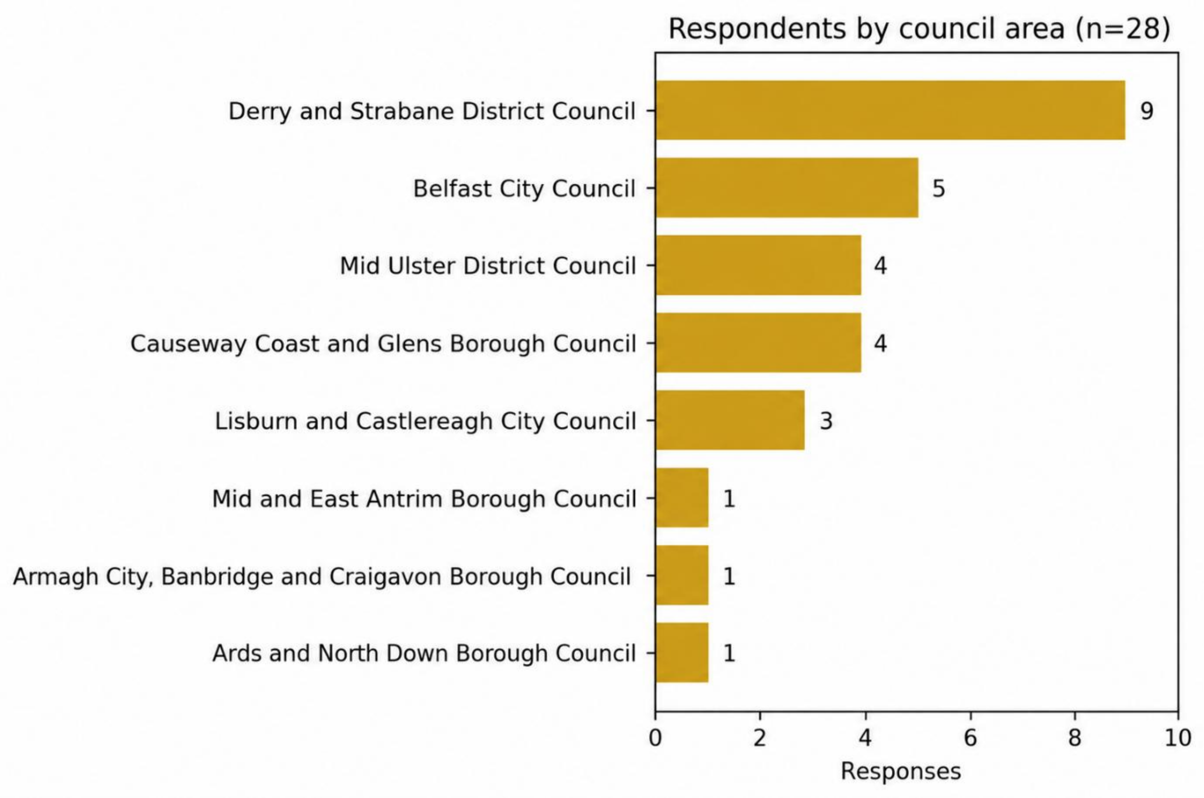
Respondent type	Count	Percentage
Person diagnosed with Skin cancer	25	89.3%
Family member/carer	2	7.1%
Bereaved family member	1	3.6%

Age



Geographical information

Responses came from **eight** Northern Ireland council areas, with the largest number from Derry and Strabane District Council.



Types of skin cancer represented

26 respondents provided a skin cancer diagnosis/type. Two respondents did not specify a diagnosis/type. Some respondents reported more than one type, so the category totals below are overlapping and should not be summed.

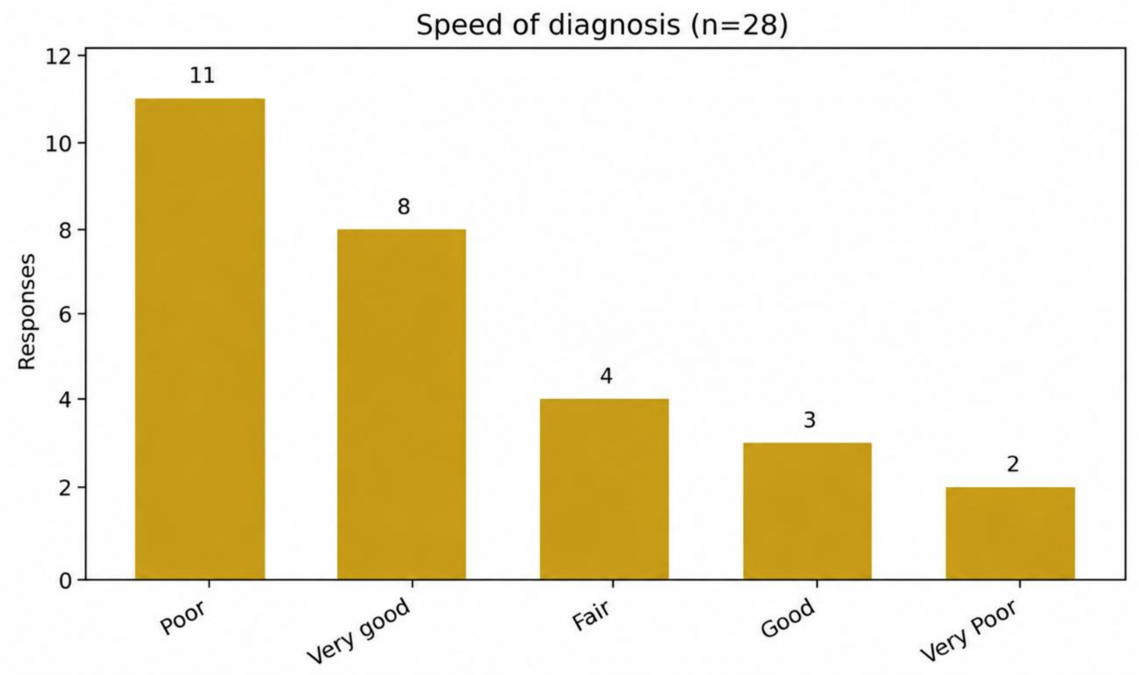
Skin cancer type/category	Respondents	Percentage of those answering (n=26)
Melanoma / lentigo maligna	17	65.4%
Basal Cell Carcinoma / BCC	7	26.9%
Squamous Cell Carcinoma / SCC	3	11.5%
Actinic Keratosis	1	3.8%
Stage 2B – not specified	1	3.8%
No diagnosis/type specified	2	7.1%

**Spelling variations such as “Basil/Basel cell” were grouped under Basal Cell Carcinoma/BCC. “Maglinant melanoma” was grouped under melanoma. “Stage 2B” was reported without a named skin cancer type and is shown separately rather than assumed.*

Diagnosis timing and pathway experience

Most respondents who answered said diagnosis occurred within the last three years.

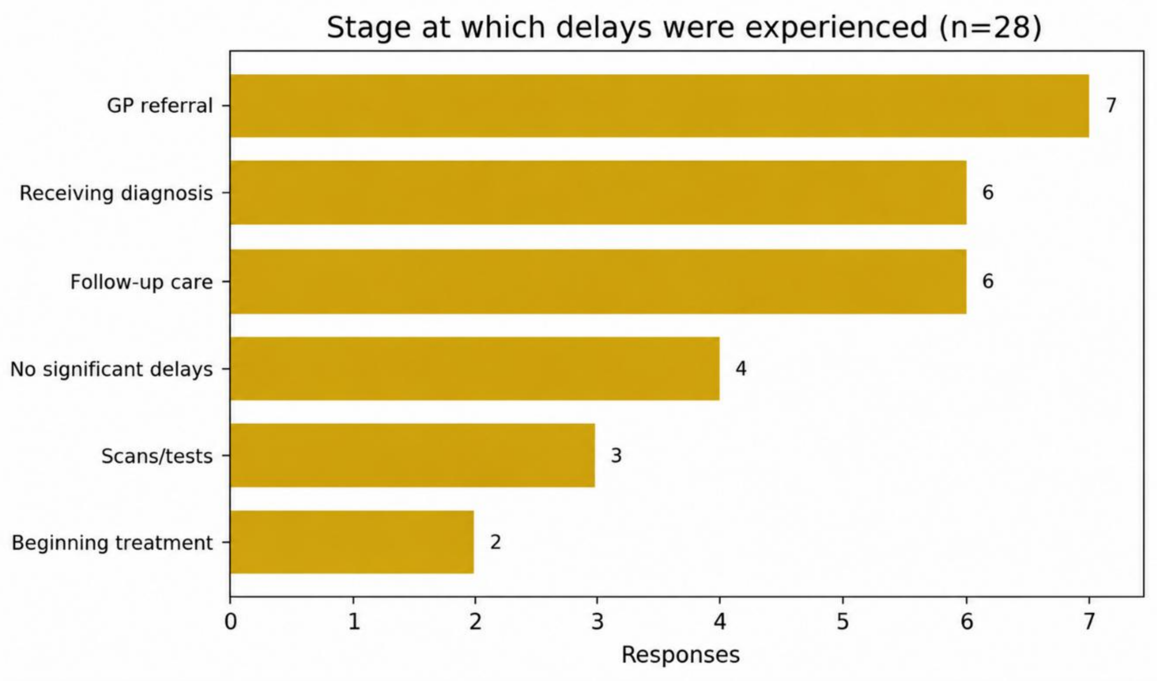
When diagnosis occurred	Count	Percentage
1-3 years ago	14	51.9%
Within the lasy year	8	29.6%
More than 7 years ago	3	11.1%
4-7 years ago	2	7.4%



On speed of diagnosis, 13/28 respondents (46.4%) selected Poor or Very Poor, while 11/28 (39.3%) selected Good or Very good. This indicates a mixed picture: some respondents experienced rapid care, while others described significant distress from delays and uncertainty.

Delay stage reported	Count	Percentage
GP referral	7	25.0%
Receiving diagnosis	6	21.4%
Follow-up care	6	21.4%
No significant delays	4	14.3%
Scans/tests	3	10.7%
Beginning treatment	2	7.1%

Delay stage reported	Percentage
GP referral	25.0%
Receiving diagnosis	21.4%
Follow-up care	21.4%
No significant delays	14.3%
Scans/tests	10.7%
Beginning treatment	7.1%



What respondents found most difficult

- Waiting for appointments, biopsy results, diagnosis, treatment plans or follow-up.
- Uncertainty between stages of the pathway, particularly where no clear timeframe or contact route was given.
- Trying to be heard at GP/referral stage, especially where symptoms were not initially treated as serious.
- Concern about follow-up, surveillance and check-ups after surgery or treatment.

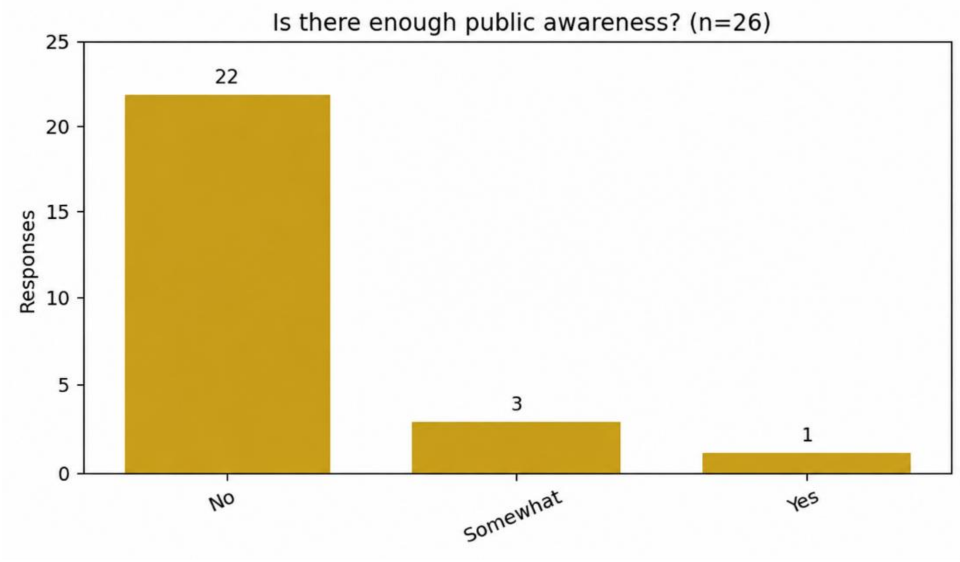
"The waiting - especially when you are already at higher cancer risk."

"Waiting times from GP to dermatology were way too long."

"The unknown timeframes are the worst."

Public awareness and prevention

22/26 respondents who answered (84.6%) said there is not enough visibility or public awareness around warning signs and early detection in Northern Ireland.



Preferred awareness messaging	Count	Percentage
Real patient stories	12	46.2%
Social media campaigns	7	26.9%
School/community education	5	19.2%
Workplace campaigns	2	7.7%

Awareness themes from comments

- Skin cancer is perceived by respondents as less visible than other cancer types in public campaigns.
- Several respondents felt Northern Ireland's climate may create false reassurance that sun exposure risk is low.
- Respondents supported real patient stories, social media campaigns and school/community education.
- Sunbed use, SPF, self-checking and photos/examples of different skin cancer presentations were mentioned as useful prevention messages.

“People are too blase about the seriousness of skin cancer. They still think it is something that can be cut out and then you carry on as normal.”

“I think due to our lack of sun in NI people don't think it affects them.”

“My friends had no clue this could happen to someone our age.”

Information, communication and involvement in care

How informed respondents felt	Count	Percentage
Sometimes	9	32.1%
Always	8	28.6%
Usually	7	25.0%
Rarely	2	7.1%
Never	2	7.1%
Felt listened to by healthcare professionals	**Count**	**Percentage**
Usually	9	32.1%
Sometimes	8	28.6%
Rarely	5	17.9%
Never	3	10.7%
Always	3	10.7%
Included in care/treatment decisions	**Count**	**Percentage**
Yes fully	12	42.9%
No	8	28.6%
Mostly	6	21.4%
Sometimes	2	7.1%

16/28 respondents (57.1%) said they were Sometimes, Rarely or Never listened to. 10/28 (35.7%) said they were No or only Sometimes included in decisions.

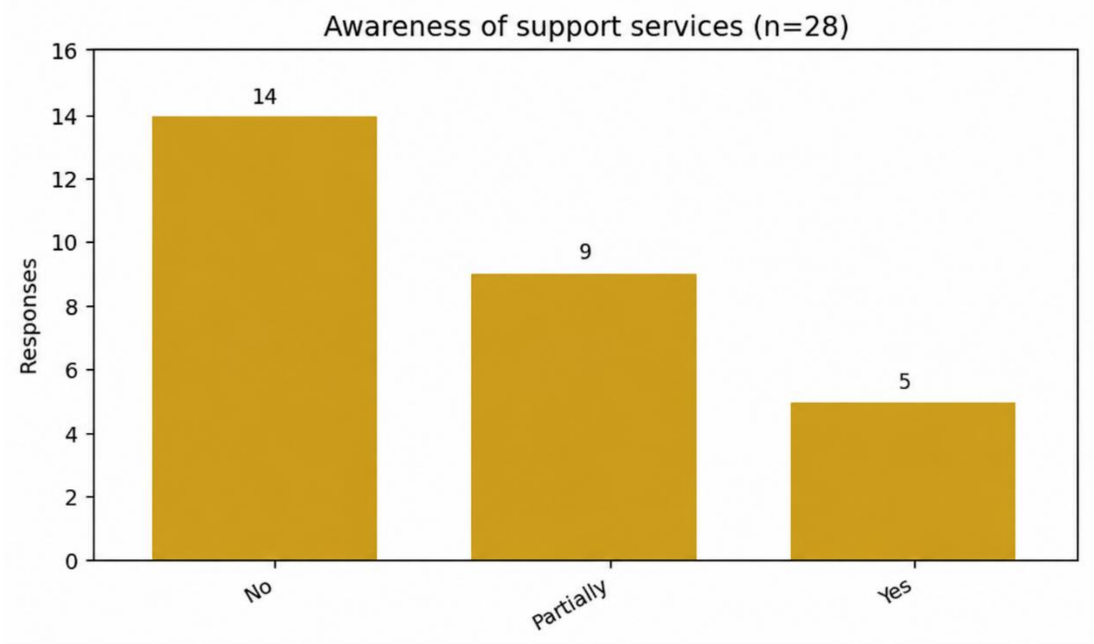
- Communication gaps were linked to anxiety, confusion and a feeling that patients had to chase information themselves.
- Some respondents described good clinical care but a lack of contact or clarity between appointments and test results.
- Information-sharing across sites/trusts was highlighted by one respondent as a safety and coordination concern.

"There was a huge breakdown of information sharing on my care."

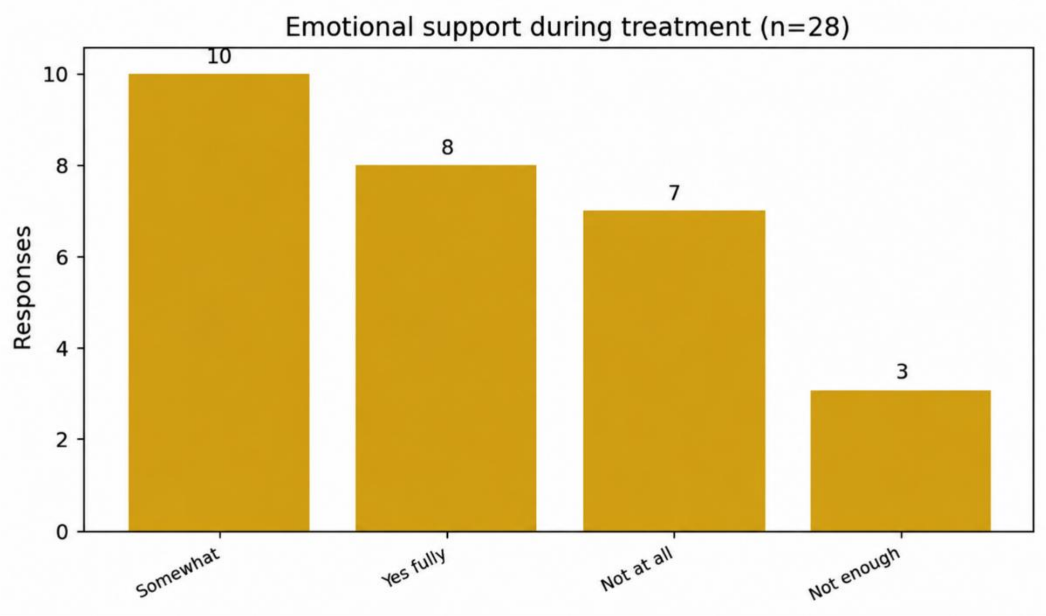
"It would be useful to have some form of contact between initial excisions and biopsy results."

"Trying to convince the GP that something was wrong was most difficult."

Support, emotional wellbeing and practical barriers



14/28 respondents (50.0%) were not aware of support services, charities or community resources, and 9/28 (32.1%) were only partially aware.

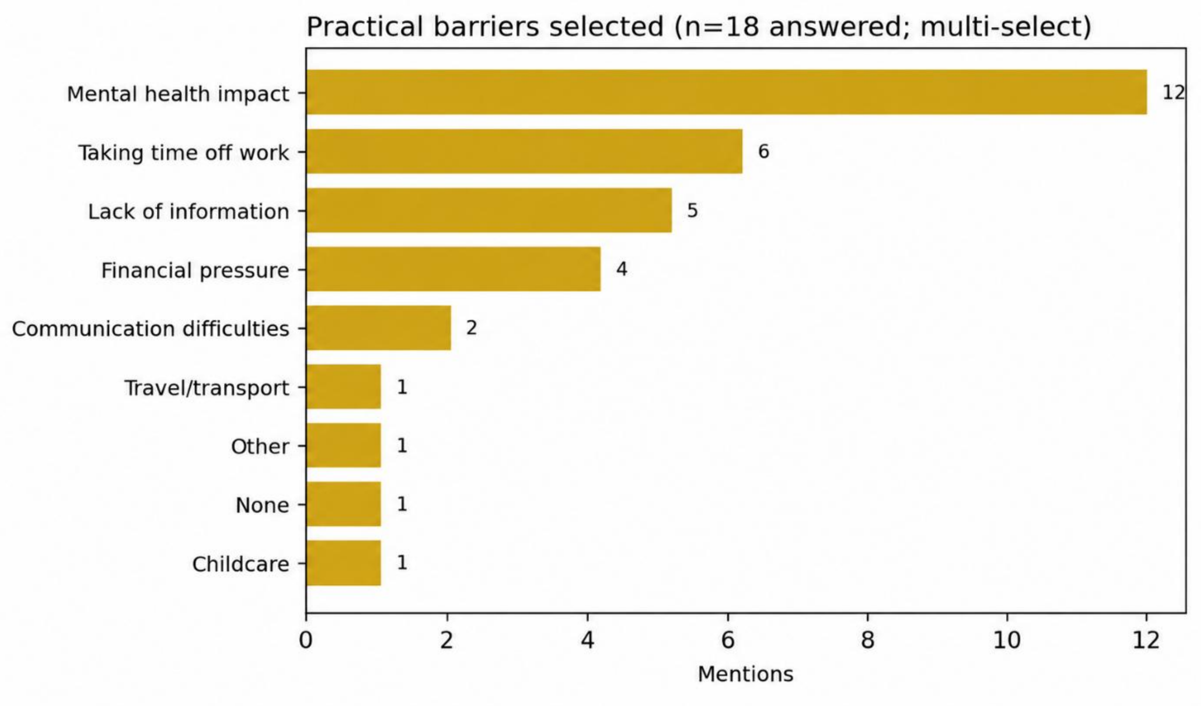


10/28 respondents (35.7%) felt Not at all or Not enough emotionally supported during treatment. Psychological/counselling support was reported as Easily available by only 3/28 respondents (10.7%).

Psychological/counselling support availability	Count	Percentage
Unsure	14	50.0%
Available but difficult to access	6	21.4%
Not available	5	17.9%
Easily available	3	10.7%

Support for family/carer support, 13/28 respondents (46.4%) answered No and 10/28 (35.7%) were Unsure.

Practical barriers affecting care



**Practical barriers question: 18 respondents selected at least one option. It was a multi-select question, so counts represent mentions, not unique respondents.*

> *“Speaking with people who actually went through the same journey would have helped.”*
>
> *“Counselling along with diagnosis.”*
>
> *“More information on skin cancer and more support.”*

Moving forward

For policymakers and health leaders

- Fund visible, Northern Ireland-specific skin cancer awareness campaigns that include real patient stories, symptom recognition, self-checking, SPF and sunbed messaging.
- Review dermatology and skin cancer pathway capacity, with particular attention to red-flag referral times, biopsy/result communication and follow-up backlogs.
- Create or support a recognisable skin cancer information and support route for Northern Ireland, including signposting from GP practices and dermatology services.
- Strengthen emotional, psychological and practical support offers for patients and families, including signposting at diagnosis and after treatment.
- Embed patient voices in service redesign, using lived experience to identify where delays, communication gaps and aftercare issues occur.

For GPs and primary care teams

- Treat patient-reported skin changes and concern seriously, especially where symptoms persist or the patient has risk factors or strong anxiety about change.
- Use clear safety-netting: explain what is being monitored, when to return, and what changes should trigger urgent review.
- Improve signposting to reliable skin cancer information, support charities and psychological/peer support at the point of referral or diagnosis.
- Where referrals are made, clearly explain the referral category, expected next steps and who the patient can contact if they do not hear back.
- Recognise that even “less serious” skin cancers can cause fear, uncertainty, work disruption and lasting concern for patients.

Conclusion and next steps

This survey provides a clear patient and family voice on skin cancer care in Northern Ireland. The findings show both positive experiences and areas requiring improvement. The strongest message is that awareness, timely access, communication and support should be treated as connected parts of the care pathway, not separate issues.

- Use these findings as a basis for engagement with MLAs, the Department of Health, Health and Social Care Trusts, GP federations, dermatology teams and cancer charities.
- Develop a short policy ask around skin cancer awareness, early detection and diagnostic capacity.
- Share the GP-focused findings with primary care leads to support discussion on referral, safety-netting and patient communication.
- Consider repeating the survey with a larger sample or targeted outreach to under-represented council areas and demographic groups.
- Protect respondent confidentiality by continuing to remove contact details and avoiding identifiable free-text attribution in public materials.

Appendix A: Question-by-question results

Which best describes you?

Answer	Count	Percentage
Person diagnosed with Skin cancer	25	89.3%
Family member/carer	2	7.1%
Bereaved family member	1	3.6%

Age group

Answer	Count	Percentage
40-54	14	50.0%
55-69	8	28.6%
25-39	4	14.3%
70+	1	3.6%
18-24	1	3.6%

Where do you live?

Answer	Count	Percentage
Derry and Strabane District Council	9	32.1%
Belfast City Council	5	17.9%
Mid Ulster District Council	4	14.3%
Causeway Coast and Glens Borough Council	4	14.3%
Lisburn and Castlereagh City Council	3	10.7%
Mid and East Antrim Borough Council	1	3.6%
Armagh City, Banbridge and Craigavon Borough Council	1	3.6%
Ards and North Down Borough Council	1	3.6%

Approximately when did diagnosis occur?

Answer	Count	Percentage
1-3 years ago	14	51.9%
Within the last year	8	29.6%
More than 7 years ago	3	11.1%
4-7 years ago	2	7.4%

Do you feel there is enough visibility and public awareness around skin cancer warning signs and early detection in Northern Ireland?

Answer	Count	Percentage
No	22	84.6%
Somewhat	3	11.5%
Yes	1	3.8%

What types of skin cancer awareness messaging do you think would be most effective in helping people seek earlier diagnosis?

Answer	Count	Percentage
Real patient stories	12	46.2%
Social media campaigns	7	26.9%
School/community education	5	19.2%
Workplace campaigns	2	7.7%

How would you rate the speed of diagnosis?

Answer	Count	Percentage
Poor	11	39.3%
Very good	8	28.6%
Fair	4	14.3%
Good	3	10.7%
Very Poor	2	7.1%

Did you experience delays at any stage?

Answer	Count	Percentage
GP referral	7	25.0%
Receiving diagnosis	6	21.4%
Follow-up care	6	21.4%
No significant delays	4	14.3%
Scans/tests	3	10.7%
Beginning treatment	2	7.1%

Did you feel well informed throughout the process?

Answer	Count	Percentage
Sometimes	9	32.1%
Always	8	28.6%
Usually	7	25.0%
Rarely	2	7.1%
Never	2	7.1%

Did you feel emotionally supported during treatment?

Answer	Count	Percentage
Somewhat	10	35.7%
Yes fully	8	28.6%
Not at all	7	25.0%
Not enough	3	10.7%

Was psychological or counselling support available when needed?

Answer	Count	Percentage
Unsure	14	50.0%
Available but difficult to access	6	21.4%
Not available	5	17.9%
Easily available	3	10.7%

Did family members/carers receive enough support?

Answer	Count	Percentage
No	13	46.4%
Unsure	10	35.7%
Somewhat	3	10.7%
Yes	2	7.1%

Did you feel listened to by healthcare professionals?

Answer	Count	Percentage
Usually	9	32.1%
Sometimes	8	28.6%
Rarely	5	17.9%
Never	3	10.7%
Always	3	10.7%

Did you feel included in decisions about care and treatment?

Answer	Count	Percentage
Yes fully	12	42.9%
No	8	28.6%
Mostly	6	21.4%
Sometimes	2	7.1%

Were you aware of support services, charities, or community resources available to you?

Answer	Count	Percentage
No	14	50.0%
Partially	9	32.1%
Yes	5	17.9%

Would you be willing to share more about your experience in the future?

Answer	Count	Percentage
Yes	21	75.0%
No	7	25.0%

Practical barriers affecting care

Barrier	Mentions	Percentage of those answering (n=18)
Mental health impact	12	66.7%
Taking time off work	6	33.3%
Lack of information	5	27.8%
Financial pressure	4	22.2%
Communication difficulties	2	11.1%
Travel/transport	1	5.6%
Other	1	5.6%
None	1	5.6%
Childcare	1	5.6%

Appendix B: Data quality notes

- The diagnosis field was free text. Spelling variants and combined diagnoses were coded into categories for analysis, while ambiguous entries were handled separately rather than assumed.
- Some respondents skipped individual questions; percentages therefore use question-specific denominators.

Appendix C: Thematic Analysis

Public Awareness of Skin Cancer, Warning Signs and Early Detection

Question**:** ***Do you feel there is enough visibility and public awareness around skin cancer warning signs and early detection in Northern Ireland?***

Overview

Respondents overwhelmingly felt that public awareness of skin cancer warning signs and early detection remains inadequate in Northern Ireland. While a small number acknowledged improvements in recent years, participants consistently highlighted a lack of visible public health messaging, misconceptions about risk factors, poor understanding of symptoms, and concerns that low awareness contributes to delayed diagnosis and treatment.

Six key themes were identified.

Theme 1: Insufficient Public Awareness and Visibility

Description

The strongest theme emerging from the responses was the perception that skin cancer lacks visibility compared with other health conditions. Participants repeatedly described an absence of public campaigns, educational messaging and awareness initiatives.

Illustrative Quotes

"There is no awareness in the north of Ireland only in hospitals."

"It's not often u see warnings only in docs or hospital."

"People are genuinely gobsmacked when they find out I was diagnosed with skin cancer at 19."

Interpretation

Respondents felt that many people remain unaware of:

- Common warning signs of skin cancer
- The importance of early detection
- When to seek medical advice
- The seriousness of skin cancer diagnoses

Participants suggested that awareness efforts are often only encountered after diagnosis or within healthcare settings, rather than through proactive public education.

Theme 2: Misconceptions About Risk and Vulnerability

Description

Many respondents identified persistent misconceptions regarding who is at risk of developing skin cancer.

Illustrative Quotes

"I think due to our lack of sun in NI people don't think it affects them."

"People are genuinely gobsmacked when they find out I was diagnosed with skin cancer at 19."

"People are too blasé about the seriousness of skin cancer."

Interpretation

Participants highlighted several common misconceptions:

- Skin cancer only affects older people.
- Skin cancer only occurs after holidays abroad.
- Tanning is safer than burning.
- Northern Ireland's climate reduces risk.
- Skin cancer only presents as a dark mole.

These misconceptions were viewed as barriers to both prevention and early diagnosis.

Theme 3: Need for Stronger Public Health Education and Prevention Campaigns

Description

Respondents consistently called for more visible and sustained awareness campaigns.

Illustrative Quotes

"It needs to be on bill boards, sunbeds and more on social media."

"No clear messages and awareness of the implication of sun damage."

"Patient and carer stories on social media, TV, radio, local press, posters in chemists, GP surgeries etc."

Interpretation

Participants suggested increasing awareness through:

- Billboards and public advertising
- Social media campaigns
- Television and radio messaging
- School-based education
- GP surgeries and pharmacies
- Sunbed awareness campaigns
- Patient stories and lived experience campaigns

There was a clear desire for awareness efforts similar to those seen for other cancers.

Theme 4: Awareness Linked to Delayed Diagnosis and Referral

Description

Several respondents directly connected poor awareness with delays in recognition, referral and diagnosis.

Illustrative Quotes

"I had to push for a referral to dermatology."

"Mine was on my lip for 3 years and it took that long for me to get it removed."

"I knew my own body and so glad I pushed for diagnosis."

Interpretation

Participants described situations where:

- Symptoms were not recognised promptly.
- Patients felt they had to advocate strongly for themselves.
- Delays occurred before specialist assessment.
- Earlier intervention may have been possible with greater awareness.

Many respondents believed that improved awareness among both the public and healthcare professionals could lead to earlier diagnosis and better outcomes.

Theme 5: Patient Experiences Highlight Concerns About Recognition in Primary Care

Description

A significant theme centred on concerns regarding recognition of suspicious lesions within primary care settings.

Illustrative Quotes

"When I attended my GP with a small lump on the lower leg I was told it was a wart."

"Never once did she mention dermatology or referring me on."

"I feel our GPs need to do more for skin lesions."

Interpretation

Several respondents described lengthy diagnostic journeys involving multiple consultations before referral or biopsy.

These experiences reinforced participants' belief that awareness and education regarding skin cancer warning signs should extend beyond the general public to healthcare professionals involved in early assessment and referral.

Theme 6: Awareness Often Develops Only After Personal Experience

Description

Many respondents reported that their understanding of skin cancer only increased after a personal diagnosis or the diagnosis of a family member.

Illustrative Quotes

"I hadn't heard of it until my brother was diagnosed."

"It was only after seeing a girl I followed on Instagram share her diagnosis."

Interpretation

Participants frequently described becoming aware of warning signs through:

- Personal diagnosis
- Family experiences
- Social media stories
- Patient advocacy accounts

This suggests that awareness is often reactive rather than preventative.

Theme 7: Recognition of Progress, But Continued Need for Improvement

Description

A minority of respondents acknowledged that awareness has improved over time.

Illustrative Quotes

"I feel it has slightly improved over the past year."

"Things have definitely improved since I was a child."

Interpretation

Although respondents recognised greater availability of sunscreen products and increased discussion of skin protection, they generally felt that progress has been limited and that awareness remains significantly below what is needed.

Summary

Across all responses, participants consistently expressed concern that public awareness of skin cancer warning signs and early detection remains insufficient in Northern Ireland. Respondents identified widespread misconceptions about risk, limited visibility of awareness campaigns, and concerns that poor awareness contributes to delayed diagnosis. Participants called for stronger public education initiatives, greater emphasis on prevention and sun protection, and increased recognition of both typical and atypical presentations of skin cancer. While some respondents recognised recent improvements, there was broad agreement that substantially more needs to be done to improve awareness and support earlier diagnosis.

Most Difficult Part of the Skin Cancer Journey

Question

"What part of the process was most difficult?"

Overview

Respondents identified several challenges throughout the skin cancer pathway. While individual experiences varied, the most common difficulties related to waiting for appointments, investigations and results, uncertainty during periods of waiting, communication gaps, difficulties accessing specialist services, and the emotional impact of diagnosis and treatment.

Six key themes emerged from the responses.

Theme 1: Waiting and Uncertainty Throughout the Patient Journey

Description

The most prominent theme was the emotional burden created by waiting. Respondents described prolonged periods waiting for appointments, investigations, biopsy results, surgery, and follow-up care.

Illustrative Quotes

"Waiting results."

"The waiting. I'm really struggling with the 'after' too."

"Waiting on results."

"The wait on biopsy results."

"Waiting time from diagnosis to receiving my operation."

Interpretation

Waiting was not simply viewed as an inconvenience. Participants described waiting as a source of significant anxiety, uncertainty and emotional distress. Several respondents reported feeling unable to move forward with their lives while awaiting important information about their diagnosis or treatment.

Theme 2: Delays and Barriers to Accessing Specialist Care

Description

Many respondents described difficulties accessing dermatology services, biopsies, scans and specialist assessment.

Illustrative Quotes

"Getting a GP appointment."

"Access to scans and biopsy."

"Delay from GP referral to getting seen in Dermatology."

"Told I'd be seen in September last year still waiting."

Interpretation

Participants described lengthy waits between referral and specialist assessment. In some cases, respondents reported seeking private healthcare because of concerns regarding delays within the public system.

Theme 3: Concerns Regarding Referral Processes and Care Coordination

Description

Several respondents reported challenges navigating referral systems and coordinating their care.

Illustrative Quotes

"I had never been referred."

"I have had to chase these via my GP."

"I contacted dermatology to find out about my biopsies to find I was on a different list."

Interpretation

Respondents described situations where referrals were delayed, lost, or required active patient follow-up. Many felt responsible for managing aspects of their own care pathway, including chasing appointments, results and follow-up investigations.

Theme 4: Emotional Impact of Diagnosis and Living with Uncertainty

Description

Participants described the emotional consequences of diagnosis, treatment and ongoing surveillance.

Illustrative Quotes

"Being told it was Melanoma."

"I feel like I am in limbo at the minute."

"The waiting. I'm really struggling with the after too."

Interpretation

For many respondents, the emotional impact extended beyond the point of diagnosis. Feelings of fear, uncertainty and vulnerability often persisted throughout treatment and follow-up care.

Several respondents described ongoing anxiety while waiting for results or future surveillance appointments.

Theme 5: Concerns About Follow-Up and Continuity of Care

Description

A recurring theme was dissatisfaction with follow-up arrangements and communication after diagnosis or treatment.

Illustrative Quotes

"I have had to chase these via my GP."

"This causes unnecessary worry."

"It would be useful to have some form of contact between the initial excisions and the results."

Interpretation

Respondents often felt unsupported between appointments and described limited communication during periods of waiting. Several highlighted a lack of clear points of contact when seeking information or reassurance.

Theme Statement

Respondents highlighted gaps in communication and follow-up support, particularly during periods between treatment and receipt of results.

Theme 6: Challenges in Having Concerns Taken Seriously

Description

Some respondents described difficulties convincing healthcare professionals that further investigation was required.

Illustrative Quotes

"Trying to convince the GP that something was wrong."

"I had to push for a referral."

Interpretation

These experiences contributed to feelings of frustration and loss of confidence. Respondents emphasised the importance of healthcare professionals listening to patients who identify changes in their own bodies.

Theme 7: Physical and Practical Challenges of Treatment

Description

Although mentioned less frequently than waiting and access issues, some respondents described the practical and physical impact of treatment.

Illustrative Quotes

"Treatment was hard. I've three young children so found it tough on my immune system."

Interpretation

Participants highlighted the broader impact of treatment on family life, employment, caregiving responsibilities and day-to-day functioning.

Summary

Across all responses, the most difficult aspect of the skin cancer journey was the experience of waiting. Respondents repeatedly described anxiety associated with waiting for appointments, investigations, biopsy results and treatment. Difficulties accessing specialist services, concerns regarding referral pathways, and gaps in communication further contributed to distress. Many participants reported feeling responsible for chasing appointments and coordinating aspects of their own care. Alongside these system-related challenges, respondents described the emotional impact of diagnosis, ongoing uncertainty and the practical consequences of treatment.

The findings suggest that improvements in waiting times, communication, care coordination and patient support could significantly improve patient experience throughout the skin cancer pathway.

What Support Would Have Made the Biggest Difference?

Question

"What support would have made the biggest difference to you?"

Overview

Respondents highlighted several areas where additional support could have improved their experience of skin cancer diagnosis, treatment and follow-up care. The most commonly identified needs related to improved information and communication, emotional and psychological support, timely access to care and follow-up, greater awareness of the impact of skin cancer, and feeling listened to by healthcare professionals.

While some respondents reported strong support from family members, specialist nurses or charities, many described gaps in formal support services and information provision.

Six key themes emerged from the responses.

Theme 1: Need for Better Information and Communication

Description

The strongest theme was the desire for clearer, more comprehensive information throughout the patient journey.

Illustrative Quotes

"More information and follow up appointment."

"I wish that there was just more information as to what was actually happening to me."

"More information on skin cancer."

"More leaflets explaining all the skin cancers."

Interpretation

Respondents frequently described uncertainty regarding:

- Their diagnosis
- Risk of recurrence
- Follow-up plans
- Prognosis
- Different types of skin cancer

Many felt they were left to seek information independently and would have benefited from clearer explanations at diagnosis and throughout follow-up.

Theme 2: Emotional and Psychological Support

Description

Many respondents emphasised the emotional impact of receiving a cancer diagnosis, regardless of the severity or prognosis.

Illustrative Quotes

"Emotional support and awareness."

"The word cancer is just awful."

"Maybe talking to someone."

"Are you ok would have been nice."

Interpretation

Participants described feelings of shock, anxiety, fear and uncertainty. Several respondents felt that emotional support was overlooked because skin cancer is often perceived as less serious than other cancers.

Even individuals with relatively favourable prognoses reported ongoing worry about recurrence and future health.

Theme 3: Timely Access to Care and Follow-Up

Description

Respondents frequently identified delays in diagnosis, review appointments and follow-up care as sources of distress.

Illustrative Quotes

"Speedy diagnosis."

"I should have been seen in March and have been told I will not be seen until July."

"Follow up appointment."

Interpretation

Participants viewed timely access to care as a form of support in itself. Delays contributed to anxiety, uncertainty and reduced confidence in the healthcare system.

Respondents particularly valued regular reviews and reassurance following treatment.

Theme Statement

Timely diagnosis, follow-up appointments and continuity of care were viewed as essential forms of support that could significantly reduce patient anxiety.

Theme 4: Need to Feel Heard and Taken Seriously

Description

Several respondents described experiences where they felt dismissed or unsupported when seeking help.

Illustrative Quotes

"I wanted to be heard and helped in the right direction."

"Trying to plead for help and not getting anywhere."

Interpretation

Respondents emphasised the importance of healthcare professionals listening to patient concerns and recognising that patients often identify changes in their own bodies before others.

Being listened to was viewed as a critical component of high-quality care.

Theme 5: Recognition of the Wider Impact of Skin Cancer

Description

Many respondents felt that skin cancer is often underestimated by society, employers and sometimes healthcare systems.

Illustrative Quotes

"There is a huge lack of understanding how serious skin cancer is."

"In my workplace it is just not considered."

"You have been diagnosed with cancer."

Interpretation

Participants described a perception that skin cancer is frequently viewed as a less serious cancer, leading to reduced understanding of its physical, emotional and practical impacts.

Some respondents specifically highlighted the need for greater awareness within workplaces.

Theme 6: Value of Family, Specialist Nurses and Charities

Description

While many respondents highlighted unmet needs, several also identified sources of support that had been particularly valuable.

Illustrative Quotes

"My family and knowing the nurse on my case was available."

"I was very lucky to be supported by AYA cancer charities."

"Still early days and fortunate to have good family and friends."

Interpretation

Respondents consistently valued:

- Family support
- Friends
- Specialist nurses
- Cancer charities
- Accessible points of contact

These sources often helped fill gaps where formal support services were limited.

Summary

Respondents identified information, emotional support and timely care as the forms of support that would have made the greatest difference to their experience. Many described uncertainty regarding diagnosis, treatment and recurrence risk, alongside feelings of anxiety and isolation following diagnosis. Participants emphasised the importance of clear communication, regular follow-up, being listened to by healthcare professionals, and access to emotional support. Several also highlighted the need for greater recognition of the impact of skin cancer within workplaces and wider society. Family members, specialist nurses and cancer charities were frequently identified as valuable sources of support.

Overall, the findings suggest that improvements in communication, emotional support, follow-up care and patient-centred engagement could significantly enhance the experience of individuals affected by skin cancer.

Is There Anything Policymakers or Health Leaders Are Currently Overlooking?

Question

"Is there anything policymakers or health leaders are currently overlooking?"

Overview

Respondents identified several areas where they felt policymakers and health leaders are failing to fully recognise or address the needs of people affected by skin cancer. The strongest themes related to waiting times and access to care, public awareness and prevention, referral pathways, patient-centred care, information and support, and access to primary care services.

Across responses, participants consistently expressed concern that skin cancer does not receive the same level of attention, visibility or urgency as other cancers.

Six key themes emerged.

Theme 1: Waiting Times and Delays in Care

Description

The most frequently referenced issue was delays throughout the diagnostic and treatment pathway.

Illustrative Quotes

"Cut waiting times."

"2 week targets for red flag referrals need to be met."

"Downgrading referrals to 'urgent' making crucial waiting times too long."

"Time."

Interpretation

Respondents viewed waiting times as one of the most significant challenges within the current system. Concerns focused on:

- Delays in referral pathways
- Delays in dermatology appointments
- Failure to meet suspected cancer referral targets

- Downgrading of referrals
- Delays affecting patient outcomes and anxiety levels

Participants felt that timely assessment should be a priority for healthcare leaders.

Theme 2: Lack of Public Awareness and Prevention Activity

Description

A recurring theme was the belief that skin cancer receives insufficient public attention compared with other cancers.

Illustrative Quotes

"Awareness... you hear of breast, prostate and other cancers much more than skin cancer."

"A mandate to raise and increase awareness is needed."

"There should be more information available."

Interpretation

Participants felt that awareness campaigns relating to skin cancer are limited in scope and visibility.

Many respondents believed that stronger public education could improve:

- Prevention
- Early detection
- Recognition of warning signs
- Understanding of risk factors

Theme 3: Education and Prevention Among Young People

Description

Several respondents highlighted the importance of educating younger generations about skin cancer risks.

Illustrative Quotes

"Schools to educate younger people on sunbed use."

"Enable awareness to be put in the public domain."

Interpretation

Participants felt that prevention efforts should begin earlier in life and should address behaviours such as:

- Sunbed use
- Sun protection
- Safe sun exposure
- Recognition of skin changes

Schools were frequently identified as an important setting for prevention and education initiatives.

Theme 4: Concerns About Referral Processes and Patient Navigation

Description

Participants raised concerns regarding referral systems and the ability of patients to monitor their own care.

Illustrative Quotes

"GP withholding referral – why is this?"

"The patient assumes they are referred and has no way to check."

Interpretation

Respondents described concerns that patients may be unaware when referrals are delayed, downgraded or not submitted.

Several participants felt there should be greater transparency and accountability within referral pathways.

Theme 5: Need for Better Information and Support Following Diagnosis

Description

Several respondents felt that information and support available after diagnosis remain inadequate.

Illustrative Quotes

"Yes information on skin cancer. Support after diagnose."

"There should be more information available including photos of different types of skin cancer."

Interpretation

Participants highlighted the need for:

- Clear information about skin cancer
- Visual resources showing different presentations
- Guidance on warning signs
- Ongoing support following diagnosis

Many felt that improved information could empower patients to seek help earlier and better understand their condition.

Theme 6: Patient-Centred Care and Access to Primary Care

Description

Several responses reflected broader concerns regarding patient experience within the healthcare system.

Illustrative Quotes

"I think they are overlooking basic patient care."

"Sometimes I feel I'm wasting their time."

"Lack of in person GP appointments."

Interpretation

Participants described feeling dismissed, unsupported or unable to access care when needed.

There was a perception that health services may not always appreciate the emotional impact of uncertainty and concerns about possible cancer symptoms.

Respondents emphasised the importance of:

- Listening to patients
- Access to face-to-face assessment
- Compassionate communication
- Timely support

Theme 7: Need for Enhanced Diagnostic and Monitoring Services

Description

Some respondents identified specific service improvements that could support earlier detection.

Illustrative Quotes

"Mole mapping services."

Interpretation

Participants suggested that access to additional screening and monitoring tools may improve early detection and provide reassurance for individuals at higher risk.

Summary

Respondents consistently highlighted waiting times, public awareness, referral pathways and access to care as areas requiring greater attention from policymakers and health leaders. Participants felt that skin cancer does not currently receive the same level of visibility or urgency as other cancers and called for increased prevention efforts, earlier education, improved patient information and stronger support following diagnosis. Concerns were also raised regarding referral transparency, access to primary care and the need for more patient-centred approaches to care.

Overall, the findings suggest that respondents believe improvements are needed not only in service capacity, but also in awareness, communication, prevention and patient engagement throughout the skin cancer pathway.