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Retention and evaluation of precision and generic prevention materials for melanoma: a qualitative study comparing young adults and adults

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Abstract

A randomized trial was conducted to examine whether providing precision prevention materials incorporating melanocortin-1 receptor (*MC1R*) genetic risk information would increase intention to practice melanoma preventive behaviors. Here we determine retention/evaluation of prevention materials for adolescent and young adults (AYAs) 18–39 years old vs. adults aged 40+ at 6- and 12-months as an *a priori* adjunct analysis to the primary research question.

Using qualitative methodology, open-ended questions probing most important information from prevention materials and additional comments were collected at 6- and 12-months after baseline.

Descriptive statistics were performed on demographic/self-reported characteristics. Two independent researchers applied qualitative thematic content analysis to identify major themes in open-ended questions.

Of the 1,134 participants randomized, 906 completed at least one of the follow-up surveys and contributed to analyses of intervention efficacy. Five major thematic categories emerged from the open-ended response data: 1) tips and tricks for sun protection; 2) cancer prevention; 3) risk factors and genetics; 4) general information; and 5) intervention comments. Across all

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ages, the most important information retained were sun protection techniques in the generic prevention materials group and identifying the importance of genetic risk factors/implementing lifestyle behavior changes in the precision prevention materials group. For additional comments, AYA participants in the generic prevention materials group preferred more scientific information including statistics and citations for references while adults were more likely to state they already knew cancer prevention techniques.

Results provide unique qualitative evaluation of AYA versus adult retention of prevention materials for melanoma that enhance quantitative findings.

Keywords

qualitative research; adolescent young adult; melanoma; prevention; sun-resistant; *MC1R* ; precision prevention; public health

Introduction:

Incidence of melanoma, one of the most serious forms of skin cancer, has been increasing over the past 30 years, creating a costly and significant clinical problem.[1–4] While primary and secondary prevention strategies exist including 1) wearing sunscreen, hats, long-sleeve pants and shirts, avoiding direct sun exposure and indoor tanning;[5–7] and 2) detecting melanoma at an early stage by conducting skin self-examinations or medical total body skin examinations,[8, 9] these strategies are underutilized in the United States.[10, 11]

Several factors including hair color, skin type, geographical location, history of tanning and sunburns determines the risk of developing melanoma.[12] One robust melanoma risk factor is the inherited genetic variation at the melanocortin-1 receptor (*MC1R*) gene.[13–15] Naturally occurring variation at *MC1R* is a well-established melanoma risk marker among individuals of non-Hispanic, European ancestry.[13–15] The risk conferred by *MC1R* genetic variants is strong even among individuals with phenotypes associated with average to lower melanoma risk, including those with darker natural hair, who tan well, do not severely burn, and develop fewer freckles after sun exposure.[13, 15, 16] For these individuals, *MC1R* genetic testing can reveal information about melanoma risk not otherwise deduced from clinical observation and has the potential to unmask at-risk subgroups due to genetic inheritance. The parent intervention study targeted these individuals—those with few phenotypic melanoma risk characteristics—to identify genetic information and understand hidden risk[13] (Supplemental Figure 1). Here, we qualitatively examined important prevention information and additional concerns for this subgroup of individuals with sun resistant, high risk *MC1R* variants.

While melanoma is less common in the Adolescent and Young Adult (AYA) population (18–39 years) as compared to adults (40+ years), melanoma is the third most common AYA cancer.[17] Despite education on the risks of excessive sun exposure, younger adults are typically more “sun-seeking” and experience more sunburns, increasing melanoma risk later in life.[18, 19] AYAs are also less likely to use sunscreen or other preventative measures (hats, clothing, etc.) as they report “liking to look tan”.[18, 19] It is important to evaluate

information within groups defined by periods of the life trajectory, e.g. AYA and adults, to best inform preferences, knowledge, and motivation for behavior change. Strategies to improve surveillance and prevention of risky health behaviors are needed among the general population, specifically for individuals identified at higher genetic risk.[20]

The current study was an *a priori* adjunct analysis to a randomized controlled clinical trial previously published,[13] for which the primary research question examined whether receipt of precision prevention information communicating results of *MC1R* genotyping could improve sun-related behaviors and having skin examinations among individuals with phenotypes that are associated with lower to average melanoma risk. Our objective was to compare retention and evaluation of melanoma prevention materials 6- and 12-month post-intervention among AYAs (18–39 years) and adults (40+ years) with limited melanoma risk phenotypes. We qualitatively examined retention and evaluation of precision prevention information, anchored in the Protection Motivation Theory, which theorizes an individual is more likely to adopt preventive behaviors if the behaviors are effective in eliminating the threat and the individual believes themselves capable of adopting such behaviors.[21] This study builds upon our previously published trial by providing unique qualitative evaluation of AYA and adult retention. By evaluating retention, evidence-based interventions can be designed to better support public health messaging and encourage positive health behaviors and lifestyle changes.

Materials and Methods:

Design

This was a secondary *a priori* adjunct analysis that included 1,134 participants enrolled on the "Improving My Protection Against Cancer Today-Melanoma" (*IMPACT-ME*) intervention trial, details of which have been published.[13] Participants on the trial were recruited at two primary care clinics in west-central Florida. Those eligible who also consented were block-randomized within *MC1R* risk group (average or higher) to receive either mailed precision or generic melanoma prevention materials that consisted of risk factor information (precision group only) and healthy sun behaviors (both groups) (Supplementary Materials 1). At 6- and 12-months post-intervention, participants completed surveys that included open-ended response questions probing for what they perceived as the most important information remembered from the education packet received and any additional comments they had. Surveys were completed either in hardcopy or electronically. This protocol was registered in April 2018 on clinicaltrials.gov (NCT03509467), and we followed CONSORT guidelines to report our trial design, analyses, and interpretation. The study was approved by the Institutional Review Board of the University of South Florida. All study participants signed informed consent, and the study was conducted in accordance with the Declaration of Helsinki.

Study population

For the parent study, participants 18 years of age or greater were recruited from two primary care clinics in west-central Florida between September 2015 and September 2018 and completed baseline, 6-, and 12-month surveys. Inclusion criteria included: (1) non-Hispanic;

(2) white; and (3) fluent in English. Exclusion criteria included: (1) report of a full-body skin examination within the past year; and (2) personal history of melanoma.

Participants were required to have brown/black natural hair color at 18 years of age, brown or black eye color, and at least two of the following criteria: (1) mild to no freckling at summer's end; (2) mild to no burning after exposure to a first strong summer sun; and (3) medium to dark tan after prolonged sun exposure. Brown or black eye color was later removed as a requirement and participants previously ineligible due to eye color were re-approached. Phenotypic eligibility systematically excluded individuals with Fitzpatrick skin type I, the most sun-sensitive skin type,[22] and assured that study participants had only limited phenotypic risk characteristics. This structure did result in including individuals who reported only one risk phenotype, e.g., painful, or severe burning after exposure to the sun for the first-time during summer, if other phenotypic risk factors were absent. Additional information including genotyping, randomization, and study assessments have been published.[13]

Demographic and clinical characteristics

At baseline, participants completed a study survey that elicited information on demographic and behavioral characteristics, including age, sex, ethnicity, marital status, and family history of melanoma and non-melanoma skin cancers.

Open-ended response questions

Participants completed a 6- and 12-month survey that contained two open-ended questions: (1) "Please tell us the most important information you remember from the educational packet."; and (2): "Is there anything else that you would like us to know from the health education packet?"

Data analysis

Only participants who completed at least one follow-up survey (n=906) and had the opportunity to respond to an open-ended question were included in the current qualitative analysis. The open-ended responses were analyzed using a 6-step thematic analysis approach, as outlined by Braun and Clarke, a qualitative method for identifying, analyzing, and reporting themes.[23] Thematic analysis was chosen to provide a rich description of the data and to identify themes at an explicit level using a realistic approach to build a picture of the respondents' collective experiences.[23] Due to the broad question and the manageable number of responses (n=761), manual coding of the data was chosen over computer-assisted analysis. The first author read through all open-ended responses verbatim, several times. Starting with line-by-line coding, statements related to evaluation and retention were categorized. A codebook was developed based on the common wording of descriptors. These codes were then amended and refined through discussion between the first and second author until a single list was agreed. The first author entered the list of codes into Dedoose (SocioCultural Research Consultants [SCRC]), a web application used for qualitative data analysis, and coded all the transcripts, with codes added to the list where necessary.[24] The second author then coded all transcripts to check for reliability and any discrepancies were discussed and resolved in discussion. Once the coding was agreed upon, the two researchers

reviewed the coded transcripts to search for common themes. These themes were reviewed, refined, and named and each was given a written description.

Data availability

Data were generated by the authors and de-identified data are available upon reasonable request.

Results:

Descriptive findings

Of the 906 trial participants who completed at least one of the follow-up surveys, 761 (84%) provided responses to at least one of the two open-ended questions at either 6-or 12-months, with 628 (69%) providing responses to at least one question at both timepoints. Table 1 shows characteristics of all participants. Table 2 displays participant response rates for open-ended questions at 6- and 12-months separately for AYAs and adults.

Five major thematic categories were identified from the response open-ended response data: 1) tips and tricks for sun protection; 2) cancer prevention; 3) risk factors and genetics; 4) general information; and 5) intervention comments. Thirty-nine topics of response were also identified. Table 3 shows an overview of the findings, with response frequencies reported to broadly indicate retention topics important to this group.

Qualitative content analysis

AYAs (18–39 years) on the precision prevention arm—The most common theme of the AYA precision prevention arm was the importance of understanding risk factors and genetic risk for melanoma. AYAs reported scheduling dermatology check-ups and noted the importance of being cautious in the sun due to their genetic risk. The majority of AYA participants who received higher risk genetic results reported the intention to adapt positive behavior changes. Some emotional responses were linked to participants genetic results, including short-term negative reactions at six months; however, by 12 months these reactions usually dissipated.

> ID: 101016; Male; 24 years- I was at a higher risk based on genetics. This makes me think I may need to be more careful and ask a doctor to start checking me.
>
> ID: 101082; Female; 35 – It is important to limit sun exposure and wear protective clothing, wear sunblock, avoid tanning salons, and talk with your physician.
>
> ID: 100374; Female; 28 years- This packet and information gave me a lot of anxiety. When I first signed up, I didn’t fully understand the mental health implications of knowing my genetic susceptibility. Now that I know the outcome, I’ll take precaution to reduce my risk.

As a result of knowing risk factors and genetics, AYAs in the precision prevention arm requested more frequent follow-up with intervention materials but noted they liked study reminders, such as the fridge magnet, that provided prompts for sun protection. In general,

participants in this group felt the study was useful in implementing behavior change and materials were understandable and easy to follow.

> ID: 100624; Male; 38 years- A web portal on [an] app would be nice to support this project…. I don't remember much; a refresher would be nice…. I wish it would be more ongoing…magnet, ok. App may be nice.

> ID: 100916; Female; 35 years- [The study] it provided some great information, and the magnet is on our fridge as a reminder.

AYAs (18–39 years) on the generic prevention arm

Responses that encouraged basic sun protection tips and tricks were commonly reported including the use of sunscreen, protective eyewear, and long sleeves/pants for the AYA generic arm.

> ID: 101439; Male; 38 years- Just learning about melanoma changed my behaviors. I wear sunscreen on my face no matter what if I know I'm going to be in the sun. I also wear long sleeve shirts and a neck gator [gaiter] when I go fishing or think I've had enough sun and I'm just out on the water. I didn't take these precautions before.

AYAs on the generic prevention arm felt the study was informative and they learned information they were not aware of previously. They also noted that information packets were easy to understand, and they preferred the combination of visual and written formats, which helped aid in the ease of understanding and willingness to review the packet. Many AYAs requested more science including statistics and citations for references in the information packet.

> ID: 100460; Female; 31 years- Sources cited for statistics would be appreciated. I was surprised by the age and gender statistics for which populations melanoma is most prevalent in. I would have liked to had references cited to allow further research.

> ID: 100093; Female; 24 years- There was interesting information about melanoma in the packet that I was not aware of previously.

Adults (40+) on the precision prevention arm

Adults (40+) in the precision prevention arm frequently stated they had issues interpreting risk factor information stating the information was "confusing", "hard to interpret", "the questions need to be reframed", and "it was difficult to understand [results]". They also stated that outside of risk factor interpretation, the intervention and study materials were "understandable", "detailed", "important", and "increased awareness".

> ID: 101370; Male, 54 years- The risk numbers seemed hard to interpret.

> ID: 100649; Female; 58 years- A clearer explanation of risk based on genetic results would have been helpful.

ID: 101288; Male; 66 years- Thank you for permitting me to be a part of this survey. This participation, more than a medical professional or individual, heightened my recognition of melanoma and risk.

ID: 100767; Female; 51 years - The repetition of reminders help with remembering the bottom line of safe practices and ease of compliance and importance of being smartly responsible for good prognosis.

Because of receiving risk factor information, a common theme for adults in the precision prevention arm was to conduct melanoma self-checks and discuss their results with a healthcare provider and undergo a clinical skin exam. Adults age 40 to 70 also stated the importance of implementing new behavior changes into lifestyle routines. While the oldest adults in our study (between 73 to 94 years of age) did not report on intention to change behaviors resulting from the intervention.

ID: 100581; Female; 48 years- I plan to discuss it [melanoma] with my doctor at my next appointment because of the informational packet.

ID: 100918; Female; 40 years- To get checked by a doctor. I don't normally do that.

ID: 100551; Male; 43 years- The most important thing learned is that with my genetic makeup and work being what it is, that I need to protect myself and change my bad habits while in the sun.

ID: 100077; Female; 86 years - [I will] continue my current lifestyle.

Adults (40+) on the generic prevention arm

Adults (40+) in the generic prevention arm stated they liked the layout of materials and felt the content was "readable", "very well done", "informative", "colorful", "eye-catching", and "interesting".

ID: 101475; Female; 67 years- It was a nice informative packet. My husband and mother both have had melanoma in the past and so a lot of the information I already was aware of myself.

They also were more likely to state they already knew general prevention information including statistics, rates, and survival information. Additionally, the oldest adults in our study (between 73 to 94 years of age) did not report on intention to change behaviors.

ID: 101538; Male; 58 years- Very little of it was new, so the important information, like sunscreen, clothes, hat and of course not tanning salons, was familiar.

ID: 100873; Male; 57 years- Heard this material so many times the past 20 years, it's almost part of life.

ID: 100243; Female; 61 years- It seemed to be a repeat of the same melanoma prevention materials you see all the time.

ID: 100099; Female; 83 years- At 83 years old, I shall die of something and know that dying is for all…

Commonalities between AYAs and adults:

In both AYAs and adults, participants in the precision prevention group were more likely to state intention for behavioral changes into their lifestyle routine including seeking professional and self-skin checks, avoiding sun exposure, wearing hats, wearing sunscreen, wearing long sleeve clothing and sunglasses. AYAs and adults in the generic prevention group stated tips and tricks for sun protection and general cancer prevention information were the most important and most retained information.

Differences between AYAs and adults:

AYAs in the precision prevention group reported higher understandability of genetic risk information than did adults. Adults were less likely to explore melanoma prevention topics outside of the study while AYAs requested more science, citations, and references to conduct their own independent research. Adults in the generic prevention arm were more likely to state they were already familiar with cancer prevention content than were AYAs. Adults in the precision prevention arm had difficulties interpreting risk factor information. Participants on the generic prevention arm did not receive *MC1R* genetic risk information (until after the study ended), therefore stated they were already familiar with the general prevention content; but they felt the content was easy to understand, readable, and well-done. The oldest adults in our study (between 73 to 94 years of age) in both the generic and intervention group did not report on intention to change behaviors resulting from the intervention.

Discussion:

Most genetic intervention studies have focused on dietary changes, smoking cessation, and physical activity improvements, with limited significant effects on behavior change.[25, 26] This study qualitatively examined behavioral implications of receiving personal genetic information for melanoma reported at 6-and 12-month post-intervention. Our qualitative findings support the provision of educational information about the prevention and early detection of melanoma for both AYAs and adults. This is particularly important as AYAs often view themselves as “invincible” and thus are less likely to participate in sun safe behaviors.[18, 19] Results from our study further suggest that a single intervention can be designed, refined, and disseminated using prevention materials applicable to all individuals across the lifespan, further increasing relevance and success.

Five themes of response and 39 topics of response were identified from two experienced qualitative coders. Open-ended survey responses can enhance quantitative findings and highlight concerns with study questions and materials that may inspire new avenues for research. As genetic testing becomes more widespread, personalized risk assessment results may inform behavioral responses and interventions for at-risk individuals to maximize health benefits.[27]

In our study, most participants who received higher risk genetic results reported implementing positive behavior change including avoiding direct sunlight and wearing sunscreen, sunglasses, and protective clothing. Adults and AYAs in the precision prevention groups also reported conducting more melanoma self-checks and attending dermatology

visits in response to learning about their genetic risk factors. Adults in the precision arm expressed more difficulties interpreting risk factor information, specifically stating “it was difficult to find the actual test results in the packet as it seemed to be more designed like marketing material instead of test results”, further stating they preferred “simple terms” and “dumb it down more, like a children’s book”. In this study, a health educator called participants one week after dissemination of intervention materials, allowing the opportunity for participants to ask questions and raise concerns. Future studies should also employ this method of telephone counseling for participants expressing distress or difficulty in interpreting findings. In addition to providing the *MC1R* packet, future studies may benefit by highlighting results with cartoons to explain their meaning in simplistic terms. In comparison, adults on the generic prevention arm stated they were already familiar with the general prevention content, but felt the intervention materials were easy to understand, readable, and well-done. These findings are complimentary to those of our quantitative analysis of the study prevention materials in which participants in the generic prevention arm reported somewhat higher clarity of intervention materials as compared to those on the precision prevention arm.[28] While there is limited research identifying significant impacts of genetic testing on behavior change,[13, 29, 30] the changes in prevention behaviors identified by participants suggest that our melanoma precision prevention intervention was beneficial in motivating change.

In this qualitative study, there were some short-term negative emotional reactions that were linked to receipt of higher-risk genetic results. Some participants expressed concerns understanding their genetic results and were “anxious” and “worried” after they interpreted the findings. A possible explanation is that study participants who had limited melanoma risk phenotypes may have had a preconception that their risk was low because of their phenotype. Furthermore, these reactions may have arisen, in part, because genotyping results from *MC1R*—a low to moderate penetrance gene—were conveyed in a mailed format without formal genetic counseling. Additionally, responses may have been skewed towards participants with more worry as participants who answered at least one open-ended response question at any timepoint had higher melanoma worry assessed using a 3-item adaptation of the Lerman Cancer Worry Scale[31, 32] than those who did not answer an open-ended response question ($p=0.03$). In comparison, the main analysis of our precision prevention intervention indicated that overall melanoma worry decreased post-intervention in both the *MC1R* average- and higher-risk arms, and there was an intervention effect toward less worry among those at *MC1R* higher risk.[13]

Our qualitative findings are similar to another qualitative, semi-structured interview study conducted by Fenton et al., in which participants who received personalized genomic risk assessment for melanoma reported negative initial reactions to risk including “disappointment,” “stress,” and “worry” that eventually dissipated over time.[27] Negative emotional reactions that diminish over time have been commonly cited for individuals undergoing genetic testing for high-penetrance gene, particularly for *BRCA1* and *BRCA2*.[33, 34] Our findings further indicate that genetic testing of *MC1R* may cause initial negative emotional responses that dissipate. Additional research on pre-testing risk expectations may assist in identifying individuals more likely to experience initial concerns or distress.

AYA participants in the generic prevention group preferred more scientific information including statistics and citations for references that allowed them to conduct their own independent research outside of the study while adults were more likely to state they already knew cancer prevention techniques. This supports previous research suggesting that adolescence and young adulthood is a critical period for establishing health behaviors as AYAs are more impressionable and eager to learn as a result of a range of social (peers, relationships), physical (perceived health and susceptibility), and environmental factors that influence attitudes and behaviors.[35] As AYAs are typically strongly responsive to education and training, preventive healthy lifestyle interventions to reduce risk factors associated with negative health behaviors may be particularly beneficial during this unique developmental period.[36] When examining qualitative responses across educational status (some college or more vs. high school/GED or less), there were no differences in content of themes or child codes, recognizing that the proportion of participants with lower education (high school/GED of less) was small (18.1%). However, our intervention materials were designed to minimize health literacy and numeracy demands. Regardless, this surprising finding further supports that this melanoma prevention study was adaptable across not only a variety of age ranges but also educational status. Furthermore, only a few small differences were noted between individuals with a family history of melanoma as compared to those with no family history. Only one participant with a family history of melanoma stated they were not interested in implementing behavior change as compared to twelve participants without a family history. Interestingly, only two participants with a family history of melanoma opted to discuss their genetic risk in the open-ended questions. One male participant (31 years) stated “my mother has melanoma, so I am at a higher risk” while a female participant (20 years) stated “…having a family history of melanoma… [is a] factor that predisposes me to melanoma”. However, given the small number of responses that included family history of disease, no common themes can be concluded from these results.

Study limitations should be noted. The space for open-ended responses on the online survey was restricted to text field, and thus written responses consisted of a few sentences which may limit data richness. Because the open-ended questions only solicited responses to the “most important information remembered” and “anything else you would like us to know,” information reported on behavior change (i.e., conducting self-checks, scheduling dermatology appointments, and wearing of sunscreen/protective clothing) is limited. Given our findings of an intervention effect for some primary prevention activities, it is likely participants implemented sun safety behaviors into their routine and yet did not report this information in the open-ended questions given the lack of specific query regarding behavior change. As well, it is unknown for how long participants implemented sun safety behaviors, thus our responses were limited for the specific time points in the open-ended questions. Although the addition of qualitative interviews to our study might have enhanced our findings, open-ended responses can yield meaningful qualitative insights. Because of our large sample size and high percentage of participant responses, we have confidence that our free-text analysis generated preliminary understanding of content areas for retention and evaluation of melanoma prevention materials for AYAs and adults. However, an acknowledged limitation of the study is that categorical themes of open-ended responses cannot determine causality.

There are many strengths of this study including the *a priori* conceptualization of the analysis. Additionally, our precision prevention materials were anchored in the well-known Protection Motivation Theory.[13, 21] Qualitative analysis has been increasingly recognized in research as an educational opportunity to address the "how" and "why" of research questions while enabling a deeper understanding of experiences, phenomena, and context.[37] The open-ended questions allowed us to broadly explore the retention and evaluation of melanoma prevention materials to better understand the human experience, information that cannot be easily be capture quantitatively. This qualitative study uncovered hidden strategies to implement in future research communications and intervention programs based upon preference among AYAs and adults. Furthermore, it allowed the quantitative findings, previously published,[13] to be evaluated in greater detail. Qualitative research allows groups to be identified and individualistic data can have a predictive quality for those who are like-minded, regardless of world perspective.[37] Finally, to help ensure rigor, two experienced qualitative researchers assisted with the study design and analysis of results.

Our results provide unique qualitative evaluation of AYA and adult retention of prevention materials for melanoma reported at 6- and 12-month follow-up that enhance quantitative findings. By evaluating retention, evidence-based interventions can be designed to better support public health messaging and encourage positive health behaviors and lifestyle changes. This study demonstrated that melanoma precision prevention materials that include *MC1R* genetic testing and were anchored in the Protection Motivation Theory can encourage healthy lifestyle changes to improve primary and secondary melanoma prevention activities in AYAs and adults. Further research exploring long-term adherence and retention of lifestyle changes and implementation in diverse populations is warranted.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Prevention Relevance:

It is important to evaluate information within groups defined by periods of the life trajectory, e.g., AYA and adults, to best inform preferences, knowledge, and motivation for behavior change. By assessing retention, evidence-based interventions can be designed to better support public health messaging and encourage positive health behaviors.

Table 1:

Demographic and clinical characteristics

Characteristic	Age Group	
	AYA (18–39 years old)	Adult (≥ 40 years old)
	n=294	n=612
Sex		
Female	178 (60.5%)	298 (48.7%)
Male	116 (39.5%)	314 (51.3%)
Marital status		
Single or never married	151 (51.4%)	53 (8.7%)
Married, domestic partnership, or civil union	130 (44.2%)	444 (72.5%)
Divorced, separated, or widowed	11 (3.7%)	113 (18.5%)
Education		
Graduate degree or higher	94 (32.0%)	213 (34.8%)
Four-year college degree	107 (36.4%)	175 (28.6%)
Some college	44 (15.0%)	104 (17.0%)
High school or GED	41 (13.9%)	93 (15.2%)
Less than high school or GED	4 (1.4%)	20 (3.3%)
Educated outside the U.S.	2 (0.7%)	4 (0.7%)
***MC1R* risk category**		
Average	125 (42.5%)	255 (41.7%)
Higher	169 (57.5%)	357 (58.3%)
Arm		
Precision prevention	154 (52.4%)	312 (51.0%)
Generic prevention	140 (47.6%)	300 (49.0%)
Family history of melanoma	59 (20.1%)	115 (18.8%)
Family history of non-melanoma skin cancer	79 (26.9%)	193 (31.5%)

Table 2:

Open-ended response percentages for AYAs and adults

		AYAs (18–39 years old)		Adults (≥40 years)	
Question	**Timepoint**	**Precision prevention n=154**	**Generic prevention n=140**	**Precision prevention n=312**	**Generic prevention n=300**
Please tell us the most important information you remember from the educational packet	6 months	98 (63.6%)	94 (67.1%)	188 (60.3%)	176 (58.7%)
	12 months	98 (63.6%)	91 (65.0%)	208 (66.7%)	217 (72.3%)
Is there anything else that you would like us to know from the health education packet	6 months	87 (56.5%)	78 (55.7%)	168 (53.8%)	143 (47.7%)
	12 months	77 (50.0%)	76 (54.3%)	167 (53.5%)	173 (57.7%)

Table 3:

Themes and subthemes from open-ended questions in a melanoma prevention intervention

Code	Description	Example Quote
Theme 1: Tips and Tricks for Sun Protection **(Generic prevention: n = 81 (AYA); n = 204 (adult)** **(Precision prevention: n = 55 (AYA); n = 95 (adult)** **(n = 285 generic prevention; n = 150 precision prevention)**		
Avoid sun	Any mention of avoiding the sun/sun is damaging	"Avoid sun exposure as much as possible" – 36-year-old male
Avoid tanning beds	Any mention of avoiding tanning beds	"Avoid tanning salons" – 38-year-old female
Cover-up	Any mention of covering up, including wear long sleeve shirts and pants	"To stay out of the sun midday and wear long clothing (rather than just sunscreen)" – 35-year-old female
General tips	General tips and tricks for prevention	"When I should stay out of the sun and what tactics I should adopt for sun protection" – 35-year-old female
Hats	Any mention of wearing hats, ex. wide-brim hats	"You have to wear a hat" – 37-year-old female
Lifestyle routine	Incorporated sun prevention behaviors into lifestyle routine	"Just learning about melanoma changed my behaviors. I wear sunscreen on my face no matter what if I know I'm going to be in the sun. I also wear long sleeve shirts and a neck gator when I go fishing or think I've had enough sun and I'm just out on the water. I didn't take these precautions before." – 38-year-old female
Limit sun hours	Any mention of limiting sun hours between 10 am to 4 pm	"Avoid sun between 10 am – 4 pm" – 37-year-old female
Sunglasses	Any mention of using sunglasses	"I learned that ocular tissues are as endangered by sun radiation as skin tissues. So, sunglasses are important for cancer protection, not just to make it easier to see in bright environments." – 21-year-old male
Sunscreen	Any mention of using sunscreen	"I am more mindful of reapplying my sunscreen as directed" – 28-year-old female
Theme 2: Cancer Prevention **(Generic prevention: n = 26 (AYA); n = 80 (adult)** **(Precision prevention: n = 24 (AYA); n = 59 (adult)** **(n = 106 generic prevention; n = 83 precision prevention)**		
Professional check	Any mention of seeking out a dermatologist or physician appointment	"Made me proactive about my health and I made a skin check appointment with the dermatologist." – 30-year-old female
Self-check	Any mention of self-screening for melanoma	"Checking between your toes for spots." – 27-year-old female
General prevention/protection	Any general prevention/protection measures	"Early prevention is important." – 38-year-old male
Theme 3: General Information **(generic prevention: n = 55 (AYA); n = 96 (adult)** **(precision prevention: n = 8 (AYA); n = 26 (adult)** **(n = 151 generic prevention; n = 34 precision prevention)**		
Awareness	Any mention of increased awareness of melanoma	"Melanoma is relatively common." – 39-year-old male
Prevalence	Any mention of melanoma prevalence	"I was surprised to learn how prevalent it is in the United States." – 36-year-old male
Statistics/rates	Any mention of statistics/rates of melanoma	"4 out of 100 develop melanoma." – 39-year-old female
Survival high	Any mention of survival being high	"Survival rate is high" – 39-year-old female
Survival low	Any mention of survival being low	"Much larger number of deaths than I expected" – 24-year-old female

Code	Description	Example Quote
Survival general mention	Any general mention of survival that is not high or low	“That Melanoma can still cause death and needs to be taken seriously.” – 25-year-old male
Theme 4: Risk Factors and Genetics **(Generic prevention: n = 31 (AYA); n = 39 (adult)** **(Precision prevention: n = 115 (AYA); n = 218 (adult)** **(n = 70 generic prevention; n = 333 precision prevention)**		
High risk	Participant self-identifies as high risk	“That I was high risk.” – 36-year-old female
Average risk	Participant self-identifies as average risk	“That I’m at average risk but that it’s still important to get checked out and to protect myself and my family from getting burned and sun exposure in general.” – 35-year-old female
Low risk	Participant self-identifies as low risk	“I am considered low risk” – 37-year-old female
General mention of risk	Any mention of risk that is not high, average, or low	“my risk factor” – 52-year-old male
Genetic information	Any mention of genetic testing/information	“The genetics results and seeing the stats on developing melanoma.” – 39-year-old female
Geographical location	Any mention of Florida being second leading state for melanoma	“Florida has a higher rate of melanoma than most other states” – 38-year-old male
Theme 5: Intervention Comments **(Generic prevention: n = 148 (AYA); n = 296 (adult)** **(Precision prevention: n = 156 (AYA); n = 313 (adult)** **(n = 444 generic prevention; n = 469 precision prevention)**		
Different layout	Prefer a different layout- less science, less statistics, etc.	“I remember there being a lot of information in this packet. And honestly, I found it difficult to understand. So, I remember being overwhelmed with the information and not fully comprehending the packet.” – 26-year-old female
Liked layout	Liked the current layout- readability, color, etc.	“I thought it was well produced and the infographics were well done and effective.” – 36-year-old male
Follow-up	Prefer to follow-up sooner or longer study	“No, I wish it was more ongoing.” – 38-year-old male
Magnet/reminders	Liked the reminders (ex. Magnet on fridge) would like a beach bag reminder	“Honestly, the simple reminder was effective.” – 34-year-old male
More science	Would like sources cited, more statistics, or more science	“More scientific facts regarding proteins involved and mechanism of disease progression.” – 36-year-old male
No behavior change	Did not implement a lifestyle behavior change	“My exposure to sun is me walking to and from my car (5–10 min a day or less), and I don’t really have any moles or freckles.”– 27-year-old female
Nothing	Did not learn anything	“I am a biology professor that is quite knowledgeable about skin cancer.” – 43-year-old male
Resourceful	Intervention materials were resourceful and helpful	“It was great information and very helpful.” – 35-year-old female
Share knowledge	Shared intervention materials (ex. with friend, family, or classmates)	“I try to spread the knowledge I’ve gained with others.” – 69-year-old male
Understandable	Intervention materials were understandable	“Short and to the point is good for memory” – 33-year-old male
Already aware	Participants did not learn anything from intervention	“I could write you can an entire book about the integumentary system and the incidence densities of cancers their in.” – 38-year-old male
Did not receive	Participants did not receive intervention materials	“Do not remember receiving it” – 39-year-old female
Don’t remember	Participants do not remember intervention materials	“Didn’t remember anything, sorry” – 38-year-old male