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Does personalised melanoma genomic risk information trigger conversations about skin cancer prevention and skin examination with family, friends and health professionals?

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What's already known about this topic? The few studies examining disclosure of melanoma-related genetic test results to family members have been limited to high risk individuals with a family or personal history of melanoma, and have followed testing for variants in single genes of high or moderate penetrance. Little is known about reactions of the general population to melanoma genomic risk information (based on common, low-moderate penetrance variants) and whether this information can trigger conversations about melanoma prevention and skin examinations.

What does this study add? This mixed-methods study found that receiving personalised genomic risk of melanoma information prompted conversations about sun protection (e.g. sunscreen use) and skin examinations, particularly with family and health professionals, and general conversations about melanoma risk with friends. The concept of 'shared risk' was often used when discussing

personalised risk information with family members. Communication with health professionals was more frequent among high-risk participants.

What are the clinical implications of the work? Providing personalised melanoma genomic risk information to the general population can prompt risk-appropriate discussions about skin cancer prevention and skin screening behaviours with family and health professionals. Sharing personalised risk information with others might increase the impact of receiving this information on melanoma prevention and skin examination behaviours, and this process could be used to encourage healthy behaviour change within families.

ABSTRACT

Background: Receiving information about melanoma genomic risk might trigger conversations about skin cancer prevention and skin examinations.

Objectives: To explore conversations prompted by receiving personalised genomic risk of melanoma with family, friends and health professionals.

Methods: We used a mixed-methods approach. Participants without a personal history and unselected for a family history of melanoma (n=103, aged 21-69, 53% women) completed questionnaires 3-months after receiving a personalised melanoma genomic risk assessment. Semi-structured interviews were undertaken with 30 participants in high, average and low-risk genomic risk categories, and data were analysed thematically.

Results: From questionnaires, 74% of participants communicated their genomic risk information with family, 49% with friends. Communication with a health professional differed by risk level: 41%, 16% and 12% for high, average and low-risk, respectively (P=0.01). Qualitative analysis showed that perceived 'shared risk' and perceived interest of family and friends were motivations for discussing risk or prevention behaviours. The information prompted conversations with family and health professionals about sun protection and skin checks, and general conversations about melanoma risk with friends. Reasons for not discussing with family included existing personal or family health concerns, or existing high levels of sun protection behaviours among family members.

Conclusions: Personalised melanoma genomic risk information can prompt risk-appropriate discussions about skin cancer prevention and skin examinations with family and health professionals. Sharing this information with others might increase its impact on melanoma prevention and skin examination behaviours, and this process could be used to encourage healthy behaviour change within families.

INTRODUCTION

Melanoma is highly preventable through behaviours such as sunscreen use and reduced sun exposure.[1,2] Clinical or self-conducted skin examinations also increase the likelihood of early detection and improved melanoma outcomes.[3,4] However, these behaviours remain sub-optimal in the Australian population,[5] and there is a need for further preventive strategies to reduce the impact of melanoma on the community and associated economic costs.[6] Providing the public with personalised information on their genomic risk of developing melanoma is a potentially feasible and acceptable strategy,[7] and together with written information on sun protection and skin examination, might encourage improved skin cancer prevention behaviours.

According to the Health Belief Model, health behaviours are influenced by perceived susceptibility to diseases and disease severity, perceived benefits and barriers to undertaking behaviours, awareness about health behaviours, and self-efficacy.[8] Accordingly, preventive behaviours for melanoma are influenced by factors such as perceived melanoma risk and perceived benefits of sun protection or skin screening.[2] Behavioural risk factors for chronic diseases often cluster among family and friends.[9,10] Theories of interpersonal behaviour suggest that engaging family and friends in discussions about disease risk might facilitate understanding their behaviours and disease risk as communal issues that require group action.[9,11] Discussing personalised genomic risk information with family and friends could lead to improved risk perception, prevention and skin examination behaviours, for the individual recipient and their family and social networks.[9,12,13] Personalised genomic risk information might also trigger conversations with health professionals about melanoma risk, prevention and screening. Skin examination behaviours have been found to be influenced by doctor recommendations.[2,14,15]

Exploring the type of conversations prompted by receiving melanoma genomic risk information could help to facilitate and maximise opportunities to improve melanoma prevention and early detection. The few studies examining disclosure of melanoma-related genetic test results to family members are limited to high-risk individuals with a family or personal history of the disease, and/or variants in single genes of high or moderate penetrance.[12,13,16,17] Compared to discrete high-penetrance gene mutations, inheritance of genomic (polygenic) risk is more complex because the risk estimate is based on the cumulative effect of inheriting multiple risk alleles that have low-moderate penetrance.[18] These more modest changes in risk are likely to be perceived as less threatening.[9] However, genomic risk information is not limited to high-risk families and may be perceived as relevant for health by a wider range of individuals. For these reasons, providing genomic risk information probably triggers different types of conversations.

Using a mixed-methods (quantitative and qualitative) approach,[19] we aimed to examine whether giving personalised melanoma genomic risk information to the public (without a personal history

and unselected for family history) triggered conversations about skin cancer prevention and skin examination with family, friends and health professionals. In this exploratory study, we were interested in factors influencing sharing this information, how risk was discussed, what prevention and skin screening behaviours were communicated (if any), and whether communication differed by risk category.

METHODS

Mixed-methods study design

This was a sub-study of a pilot randomised controlled trial that examined the feasibility, acceptability and preliminary impact of delivering personal genomic risk of melanoma information to the public.[7] For this sub-study, we used quantitative and qualitative methods to explore the communication patterns and conversations triggered by melanoma genomic risk information.[19] Data were collected from 1) questionnaires completed by parent trial participants after receiving risk information, and 2) qualitative interviews conducted with a subgroup (Fig. 1). We followed a triangulation design by bringing our findings from the quantitative and qualitative methods together at the reporting and interpretation stages.[20] This approach is well-suited to studies in which the process and context of participant experiences are important to the research aims.[19] Here, we jointly present and interpret the mixed-methods data, following the Standards for Reporting Qualitative Research.[21] Ethics approval was obtained from The University of Sydney and written consent was obtained from all participants.

Recruitment of participants

Participants in the parent trial[7] were recruited from the Cancer Council New South Wales (Australia) *Join a Research Study* database, comprised of people who have agreed to be contacted for ethically-approved cancer research studies. Inclusion criteria were: living in New South Wales and aged between 18-69 years. Those with a personal history of melanoma were excluded, but having a family history of melanoma did not impact study eligibility. Consent to participate was 41%.

After completion of the parent trial, we invited 41 participants, by post, to take part in a 30-45 minute semi-structured interview to further explore and provide context to the data collected via questionnaires. We purposively sampled participants to obtain comparable numbers by sex, age-group and genomic risk level (high, average, low) to ensure a range of views. We recruited in batches until no new themes or sub-codes were identified in the data (i.e. data saturation[22]) after five consecutively coded interviews. Of those invited, 34 (83%) agreed to participate and 30 were

ultimately interviewed, three in-person and all others by telephone. Reasons for declining participation included not being available or lack of time.

Procedures for providing personalised melanoma genomic risk information

Participants in the parent trial provided a saliva sample for DNA testing.[7] The MassARRAY iPLEX® Gold assay was used to genotype 42 variants (SNPs) from 21 genes/regions known to be associated with melanoma. The genotypes were used to calculate personalised genomic risk estimates, which were presented in a hard-copy booklet as 1) a relative risk, 2) a risk category: low (bottom 25%), average (middle 50%) or high (top 25%), and 3) a remaining lifetime risk, which ranged from 0.2% to 9.3% (median 2.3%) for women and from 0.6% to 19.5% (median 3.9%) for men) (Supplementary Fig. 1). The booklet contained a paragraph on "*What does this information mean for my relatives*" but did not provide recommendations of how to discuss preventive behaviours or shared risk with family members. All participants received a telephone call from the genetic counsellor around the time of receiving their risk booklet. They were also given a general information booklet on melanoma prevention and skin examinations.

Quantitative data collection and analysis: questionnaires

Three months after receiving their personalised risk information, 103 of 118 (87%) participants completed a questionnaire that included items about communication. They were asked whether they had discussed their genomic risk information with their family, friends and health professionals, and if so, to specify which health professional(s) and family member(s), and the number of friends to whom they communicated this information. Regarding communication with family members, participants rated the importance of different factors related to their decision to discuss (or not discuss) their genomic risk information with family on a 5-point Likert scale (from 'not at all important' to 'very important'), based on questionnaire items from a study that assessed motivations and barriers to family communication among recipients of genetic testing results.[23] P-values for differences by genomic risk category, sex, age, and family history were obtained from chi-square and ANOVA tests.

Qualitative data collection and analysis: interviews

The questionnaire data informed the development of the semi-structured interview guide. For example, in the questionnaires we asked participants whether or not they discussed their risk information with health professionals, and in the interviews we explored *why* they discussed their risk information (or why not). We also explored factors that motivated or discouraged sharing risk information with family, beyond those measured in the questionnaire, as well as with friends and

health professionals. We drew on qualitative research literature[20,24] and research team expertise to develop the interview questions. A draft interview guide was piloted with consumers and other researchers and then finalised (Supplementary Table 1). Interviews were conducted by AKS, audio-recorded and professionally transcribed.

The interview data were analysed thematically, which involved reading the transcripts several times, developing a coding framework, coding all the data in a systematic fashion, and searching, reviewing and defining themes across the transcripts.[25,26] We searched for themes according to sex, age and genomic risk category. The coding was undertaken using NVivo qualitative data analysis software (NVivo 10). The coding framework was developed through an iterative process of reading the transcripts and discussion with the research team. We relied on an inductive approach to thematic analysis, that is, we derived codes and themes from the data itself, as opposed to drawing on pre-selected theoretical concepts to guide the analysis.[20,26] Coding was conducted by AKS, AEC and PF who met regularly to compare coding and discuss discrepancies, which were resolved through consensus.

RESULTS

Participants

Participant characteristics are shown in Table 1. The mean age was 53 years. Participants were not selected according to family history of melanoma, however just over one quarter had a family history of melanoma.

Quantitative results: questionnaires

In the questionnaires, 74% of participants reported discussing their genomic risk information with family, and 49% with friends. Fewer communicated with a health professional, but this differed by risk level (41%, 16% and 12%, for high, average and low-risk, respectively, P=0.01) (Table 2). Communication with health professionals was mostly with general practitioners but participants also shared their risk information with skin cancer clinic doctors and dermatologists. When stratified by sex, age and family history there were no statistically significant differences in discussing risk information with family, friends and health professionals (Table 2). Among people who communicated their risk information with family, 65% discussed with partners, 25% with parents, 17% with siblings and 32% with children. Of participants who communicated with friends, they reported discussing their risk information with an average of four friends (standard deviation 2.8).

Factors influencing the decision to share: Participants who did share their risk information with their family rated the importance of several factors in their decision to discuss their risk (Table 2).

There were no significant differences between the risk categories in rating these factors. When stratified by age, participants aged 45-69 years were more likely to rate 'to fulfil a duty to inform' as important compared to those aged 18-44 years (Table 2).

Factors influencing the decision not to share: Participants at high genomic risk were more likely to report 'they're not at risk' as a factor that influenced their decision not to inform family members, whereas 'I'm having difficulty coping' was the least important factor that influenced their decision (Table 2).

Qualitative results: interviews

Factors influencing the decision to share: In the interviews, we explored factors that influenced discussions about genomic risk with family, friends and health professionals. For example, participants described factors such as wanting to raise awareness about melanoma risk (Table 3), and perceived family interest in the information. Conversations with friends were motivated by perceived interest of their friends in the genomic risk information (Table 3). A perception of a shared concern about personal skin cancer risk among friends was particularly evident among participants aged 45-69 years.

The questionnaire data revealed that the likelihood of sharing risk information with a health professional differed by risk category. However, in the interviews we found that the underlying motivating factors were similar across genomic risk categories: participants who did inform a health professional were generally motivated by wanting to update them with the information (Table 3).

Factors influencing the decision not to share: In the interviews, participants described reasons for not discussing their genomic risk with family such as existing or previous health problems and existing sun-related positive health behaviours and awareness among family members (Table 4). Participants described a lack of interest and no opportunity for discussion as reasons for not sharing their risk information with friends (Table 4). Common reasons for not sharing genomic risk information with a health professional included having a different purpose for the consultation, and not requiring further information about their melanoma risk (Table 4).

Content of conversations, and reactions of others: We explored the content of conversations and participants' perceived reactions of others to the genomic risk information using qualitative methodology only. Table 5 summarises the themes from participant conversations about melanoma genomic risk. When discussing their risk information with family members, the concept of 'shared risk' was mentioned, mainly by those at high risk but also some at low and average-risk, to frame the explanation of their chances of developing melanoma. This shared risk was linked to sharing DNA and phenotypic characteristics such as skin colour. Sun protection was also raised in family

discussions for participants of all genomic risk categories. There were no obvious patterns in the content of conversations or communication patterns according to age groups. Women generally spoke more about encouraging sun protection among family members, and also tended to describe existing or previous health concerns for themselves or among family members as a factor influencing the decision not to share.

Family, friends and health professional reactions to conversations with study participants about melanoma genomic risk information are shown in Table 6. Overall, participants who discussed their risk information perceived their family members to be supportive and interested in the information. One participant at high genomic risk reported that his wife was initially worried, but that this worry had subsided because she was reassured by how proactive the participant was with sun protection. Participants also described how conversations encouraged improved sun-protection and screening behaviours among family members, and this was particularly evident among those at high genomic risk.

Genomic risk information was generally discussed with friends briefly or in passing, which appeared to be linked to a perception of the risk information as not a 'major' or serious issue (Table 5). There was less of an emphasis on encouraging prevention and skin examination behaviours in discussions with friends (Table 5). Reactions from friends were described as positive and supportive by participants (Table 6).

Some participants, particularly those at high-genomic risk, reported receiving advice from their doctor about sun protection and skin examinations (Table 5). Participants described brief discussions with their general practitioner, mainly in which the doctor acknowledged the information, and one skin specialist explained that the participant's care would not change in light of the risk information (Table 6).

DISCUSSION

This mixed-methods study is one of the first to explore communication triggered by receiving personal genomic risk information in people unselected for personal or family disease history, and to include communication with family, friends and health professionals. Most other studies exploring communication about DNA-based melanoma risk information have focussed on family discussions, which were reported by 74% of participants in our study. Hay et al[13] found that 139 participants with a first-degree relative with melanoma who received hypothetical positive risk feedback (based on confirmed high-penetrance *CDKN2A* mutations or moderate-penetrance *MC1R* variants or higher mole count) had higher intended discussions with family members (92%),

compared to participants who received negative risk feedback (72%). Wu and colleagues[12] examined discussions about melanoma prevention with children and grandchildren among adults who received *CDKN2A* genetic test results; carriers (73%) discussed screening and risk behaviours more frequently than non-carriers (23%), and discussions about preventive behaviours declined over time for both groups.[12] In a study that examined family communication of melanoma risk (based on traditional risk factors) and preventive health behaviours in response to a web-based intervention, Bowen et al found that about two-thirds of participants discussed their risk with their family.[27]

We did not find that sharing risk information with family members or discussing sun protection behaviours differed by genomic risk category. However, a theme in family conversations about genomic risk that was more evident in participants at high and average genomic risk was the concept of 'shared risk' (applied to shared genes and shared skin characteristics). It is interesting that 'shared risk' was communicated in the context of receiving genomic risk information, because whilst relatives would be expected to be similar genetically, a person's melanoma genomic risk is based on the cumulative effect of inheriting multiple risk alleles across the 21 genes incorporated into the genomic risk estimate. Thus, there would be inter-individual variation in the inheritance of individual variants and their cumulative influence on the genomic risk estimate, and overall melanoma risk is also mitigated by sun protection behaviours. Therefore, discussions about inheritance of risk and implications for relatives may be more complex than for single-gene mutations.

The questionnaire data showed that among participants who did not communicate with family, those at high genomic risk were more likely to report 'family members not being at risk' as a reason for deciding not to discuss their risk information. This may be because they viewed it as being only relevant to themselves, perhaps unlike those who did discuss their risk information and used the concept of 'shared risk' in conversations with family. Bowen et al also highlighted that shared understanding and beliefs about melanoma risk among family members are important influences on communication within families.[27]

Almost half of the participants in our study (49%) discussed their risk information with friends. In a study of information-seeking and sharing behaviour following genomic testing for type 2 diabetes among 300 participants, 41% shared their risk information with a close friend.[28] Communicating with friends is important to skin cancer prevention behaviours, which have been linked to social and cultural norms, such as valuing the appearance of tanned skin.[29] Adults with positive attitudes towards sun-safe behaviour are likely to perceive their friends' approval and support of these behaviours,[30] and preventive behaviours, particularly in young Australians, are influenced by their

friends' attitudes and beliefs.[29] In our study, participants described conversations with friends more generally than with family, and there was less encouragement of preventive behaviours in conversations with friends. However, general conversations with friends about melanoma risk may be influential on risk perception.

Wu et al's study identified barriers to communicating about melanoma risk such as a need for additional resources on the rationale for implementing preventive behaviours, and practical ways to facilitate discussions about preventive behaviours, particularly with younger family members.[12] These were not identified as barriers in our study; however, our earlier focus group research[31,32] did identify the need for information about practical ways to reduce risk, and this information had consequently been provided to participants in our study alongside their genomic risk information.

Findings are now emerging in several contexts regarding sharing genetic test results with health professionals. In a study of the comprehension and data-sharing behaviour of 122 direct-to-consumer genetic test (DTC) customers,[33] 11% of participants shared their results with a health professional, which is comparable to those at low (12%) and average (16%) genomic risk in our study. Unlike our study, the DTC approach offers DNA-based information for a range of diseases usually without genetic counselling, testing is often marketed as 'recreational', and information on prevention strategies is not routinely provided. In our study, participants at high-genomic risk were significantly more likely to share their genomic risk information with a health professional (41%) compared to those at low and average genomic risk. Participants at high and average genomic risk reported receiving advice from their doctor on sun protection and skin self-examination, and some scheduled clinical skin examinations.

Our results indicate that providing melanoma genomic risk information to the public might be useful for increasing awareness, prevention and skin examination for people at high risk through discussions with their doctor. Participants who decided to share their risk information with family members rated the factor "difficulty coping" very low in terms of importance. This finding is in line with other studies, which have found that people tend to show low distress upon learning about their genetic risk.[16,34] Our observation that communication with a health professional was more prevalent in those at higher risk also suggests that health services may not be overburdened, and that those at lower genomic risk will not engage in over-screening. The potential to cause unnecessary harm to individuals and their families, for example over-screening, is an ethical consideration involved in delivering genomic risk information to the public. The largely positive and neutral interactions prompted by receipt of genomic risk information in our study suggest that delivering this type of information to the public is acceptable.

The participants in our study were recruited from a research database and just over one quarter had a family history of melanoma, so they may have been more engaged in communicating their genomic risk compared to the general population. We did not find that family history of melanoma influenced communication patterns, which may be because people with a family history of melanoma have already had prior discussions with family and health professionals about their melanoma risk. Further research could explore how pre-existing perceptions of shared melanoma risk (e.g. based on skin type) impact conversations about genomic risk with family and friends, as well as changes in the frequency of discussions before and after receiving melanoma genomic risk information.

In conclusion, our results show that receiving personalised genomic risk of melanoma information prompted conversations about sun protection; particularly with family and health professionals, and general conversations about melanoma risk with friends. Melanoma is largely preventable and even modest changes to sun protection and skin examination behaviours at a population level could have a significant impact on melanoma prevention and early detection.[35]

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Figure legend

Figure 1. Study flow chart

Table 1: Participant characteristics

Characteristic	Questionnaires (n=103)	Interviews (n=30)
Age, mean (range)	53 (21-69)	53 (24-69)
Female, N (%)	54 (53%)	15 (50%)
Highest level of education, N (%)		
High school or equivalent	14 (14%)	7 (23%)
Trade/diploma	35 (34%)	9 (30%)
University degree or higher	54 (52%)	14 (47%)
Family history of melanoma, N (%)	30 (29%)	8 (27%)
Genomic risk category, N, (%)		
High	29 (28%)	12 (40%)
Average	49 (48%)	8 (27%)
Low	25 (24%)	10 (33%)

Table 2: Communication outcomes collected via questionnaires

Questionnaire items	Melanoma genomic risk category			Sex		Age (years)		Family history of melanoma (Yes/No)[1]	
	Low (n=25)	Average (n=49)	High (n=29)	Female (n=54)	Male (n=49)	18-44 (n=28)	45-69 (n=75)	No (n=60)	Yes (n=30)
Have you discussed your genetic risk information with a health professional (eg doctor, dermatologist)? (N, %)									
No	22 (88%)	41 (84%)	17 (59%)	45 (83%)	35 (71%)	22 (79%)	58 (77%)	48 (80%)	23 (77%)
Yes	**3 (12%)**	**8 (16%)**	**12 (41%)[2]**	9 (17%)	14 (29%)	6 (21%)	17 (23%)	12 (20%)	7 (23%)
Did you discuss your genetic risk information with any of your friends? (N, %)									
No	12 (48%)	28 (57%)	13 (45%)	29 (54%)	24 (49%)	13 (46%)	40 (53%)	31 (52%)	16 (53%)
Yes	13 (52%)	21 (43%)	16 (55%)	25 (46%)	25 (51%)	15 (54%)	35 (47%)	29 (48%)	14 (47%)
Did you discuss your genetic risk information with any family members? (N, %)									
No	5 (20%)	17 (35%)	5 (17%)	14 (26%)	13 (27%)	4 (14%)	23 (31%)	14 (23%)	8 (27%)
Yes	20 (80%)	32 (65%)	24 (83%)	40 (74%)	36 (74%)	24 (86%)	52 (69%)[3]	46 (77%)	22 (73%)
How important were each of the following in your decision to inform your family members? (Mean, SD)[4]									
To obtain emotional support	2.0 (1.4)	2.3 (1.4)	2.5 (1.5)	2.0 (1.2)	2.6 (1.6)	2.0 (1.3)	2.4 (1.5)	2.1 (1.3)	2.5 (1.6)
To get advice about decisions regarding preventive behaviour or skin checks	2.4 (1.5)	2.6 (1.6)	2.8 (1.7)	2.4 (1.6)	2.8 (1.5)	2.2 (1.4)	2.8 (1.6)	2.5 (1.7)	2.7 (1.4)
To suggest that they get genetic testing	2.7 (1.7)	2.7 (1.6)	2.9 (1.5)	2.5 (1.6)	3.0 (1.6)	2.6 (1.7)	2.8 (1.6)	2.6 (1.5)	3.0 (1.6)
To inform them of your risk information	4.1 (0.9)	3.7 (1.2)	4.2 (1.0)	3.9 (1.1)	4.0 (1.1)	3.8 (1.1)	4.1 (1.1)	3.9 (1.1)	4.1 (1.1)
To fulfil a duty to inform	2.7 (1.5)	3.1 (1.5)	3.5 (1.5)	2.9 (1.6)	3.3 (1.4)	**2.6 (1.4)**	**3.3 (1.5)[5]**	3.1 (1.5)	3.0 (1.5)
How important were each of the following in your decision NOT to inform your family members? (Mean, SD)[6]									

I'm not close to them	2.0 (1.3)	1.8 (1.3)	2.7 (1.7)	1.6 (1.0)	2.5 (1.6)	1.4 (0.9)	2.2 (1.4)	2.2 (1.5)	1.6 (0.9)
I'm not in contact with them	2.0 (1.3)	2.0 (1.5)	2.3 (1.7)	1.6 (1.2)	2.6 (1.6)	1.2 (0.4)	2.2 (1.5)	2.3 (1.6)	1.5 (0.8)
They wouldn't care	2.7 (1.6)	1.6 (1.0)	2.3 (1.5)	1.7 (1.2)	2.2 (1.4)	1.0 (0.0)	2.1 (1.3)	2.0 (1.5)	1.6 (0.9)
I didn't want to upset them	1.7 (1.0)	1.6 (1.2)	3.3 (1.8)	1.8 (1.3)	2.3 (1.7)	1.6 (1.3)	2.1 (1.5)	2.1 (1.7)	2.1 (1.4)
They're not at risk	**2.3 (1.2)**	**1.9 (1.3)**	**3.1 (1.7)**[7]	2.4 (1.3)	2.2 (1.7)	1.8 (1.1)	2.4 (1.5)	2.2 (1.6)	2.3 (0.9)
I didn't know what to say	2.0 (1.7)	1.7 (1.1)	2.4 (1.3)	1.9 (1.3)	1.9 (1.3)	2.2 (1.3)	1.9 (1.3)	2.1 (1.4)	1.9 (1.2)
I'm having difficulty coping	1.0 (0.0)	1.2 (0.9)	1.6 (1.1)	1.3 (0.8)	1.3 (1.0)	1.6 (1.3)	1.2 (0.8)	1.4 (1.0)	1.4 (1.1)

P-values are reported only for values <0.05

[1] Participants who selected 'Unsure' for family history of melanoma have not been included in the analysis for this item (n=13).

[2] P-value comparing proportions across genomic risk categories = 0.013

[3] P-value comparing means between age groups = 0.09

[4] Only participants who selected 'Yes' for the question 'Did you discuss your genetic risk information with any family members?' rated these items on a 5-point Likert scale from: 1 – Not at all important to 5 – Very important

[5] P-value comparing means between age groups = 0.041

[6] Only participants who selected 'No' for the question 'Did you discuss your genetic risk information with any family members?' rated these items on a 5-point Likert scale from: 1 – Not at all important to 5 – Very important

[7] P-value comparing means across genomic risk categories =0.049

Table 3: Motivations to share genomic risk information with family, friends and health professionals

	Themes	Genomic risk category (sex, age)	Examples of quotes
Family	Raising awareness of genetic risk	high (female,64)	"I told my family just so they're aware of what can happen and if you've got any things on your skin that you're worried about, well do something about it, don't dwell on it."
		average (male. 66)	"Well I know my daughter's got the pool and I know she's got very white skin and she burns easily. So she didn't pick up too many of my Italian genes in skin wise anyway, but yeah, I just wanted her to be aware of it."
	Awareness of other risk factors	average (female, 45)	"I probably will at some point have a chat with them about this because I think they're probably at a higher behavioural risk than me and yeah, certainly because they're both paler than I am."
		low (female, 59)	"Family I tried to mention it. I have two sisters, one older and one younger and my youngest sister is very sun

			conscious because she has the lily white skin from the Scottish side of the family, whereas I have the olive skin."
Friends	Shared concerns about personal skin cancer risk among friends	high (male, 59)	"Probably everybody's got the same concern to a greater or lesser extent; they're aware that they're in a dangerous age for these sorts of things to be dealt with. So it's not like you go out and say, I must tell all my friends I've got this elevated cancer or melanoma risk, but I have mentioned it in passing as the conversation flowed."
		high (male, 65)	"Certainly mentioned it to a few of my colleagues at tennis because we've all got issues."
	Perceived interest of friends in the information	low (female, 25)	"I spoke about it with my friends at work because they obviously work in the area and find it interesting."
		low (female, 69)	"I have had occasion to mention it with friends, say, at my tennis club or my golf club somewhere where we're talking about being out in the sunshine and that sort of thing."
Health Professional	Desire to inform GP	high (male, 39)	"I just showed him the booklet. I pointed out that I'm a high risk, yeah."
		average (female, 54)	"I think if my doctor at the skin cancer clinic asks why I was in, I could say because I've been part of this study and now I know that my risk is just like anyone else."
		low (female, 59)	"Because you'd given the information to me and I thought, well I'll show my GP the booklet and that sort of thing."

Ta**ble 4: Factors influencing the decision to not share genomic risk information**

	Themes	**Genomic risk category (sex, age)**	**Examples of quotes**
Family	Perceived different risk factors	high (female, 51)	"I haven't spoken to my family about it; we're not super-duper close, so it sort of hasn't come up. They're all dark-haired, dark eyes and tanned, so they've got quite a different genetic makeup."
	Existing awareness and sun protection habits	average (male, 47)	"I think we're all pretty conscious of these issues because my brother and I sort of go on about it I always say, be careful of the sun, wear a hat, whenever I see them not doing that. I think we're all pretty conscious of it as a family. I think they're knowledgeable about skin cancer and being an average risk myself I thought okay, no need to mention it."
	Other past or current health concerns	high (female, 52)	"Generally I didn't talk about it with my family because I think they had enough to deal with, with me. No, I didn't want to mention me again they had enough to deal with."
		average (female, 48)	"Certainly the kids wouldn't have been interested and actually I don't think my parents would have either. They're just

			dealing with all their own health issues and unless it's major, they really don't want to know."
		low (female, 59)	"Cancer has always been a word in the family that's worried all of us so my sisters and I have always been careful of our breasts, our ovaries, et cetera. So I think every time that C-word comes up, it scares people."
Friends	Friends wouldn't be interested	high (male, 37)	"I didn't talk to them about this because the mates that I've got wouldn't pay attention to this. But most of them I suppose are egotistical and just wouldn't even worry about this."
	No relevant opportunity to share	high (male, 58)	"Well we live 30k's out of town, you know, it's pretty hard to talk to anybody. I did tell my wife's friend, but she's sun wise anyway."
		low (male, 61)	"Melanoma didn't come up in conversation and I didn't go out of my way not to tell anybody, but it just didn't come up in conversation or anything."
Health Professional	Different purpose for GP consultation	high (male, 59)	"I'm a fairly healthy specimen on the whole, I'm a typical bloke, I go to the GP when something's wrong and, I have seen her, but that was after an accident, so it probably wasn't high on my list."
		average (female, 48)	"Usually I would go to my GP if I had something else happening, so the chances of actually remembering to discuss my risk on the day, because it's not an actual issue, possibly."
		low (female, 25)	"I did go to my GP about a week ago because I was sick, but I didn't even think about it at the time, to be honest, I guess when you go to the doctor's, you've got another reason to be there."
	No need for further information from GP	high (male 69)	"I don't need any more information about it on my behalf because I think it's up to me now to get it checked out and make sure that I do all the preventative things, wearing a hat in the sun, 50 plus on me exposed areas, watching how much time I do spend in the sun without protection, getting it checked out."
		low (male, 48)	"I don't feel the need to discuss it with them. I'd like to think that I'm reasonably well informed, yes."

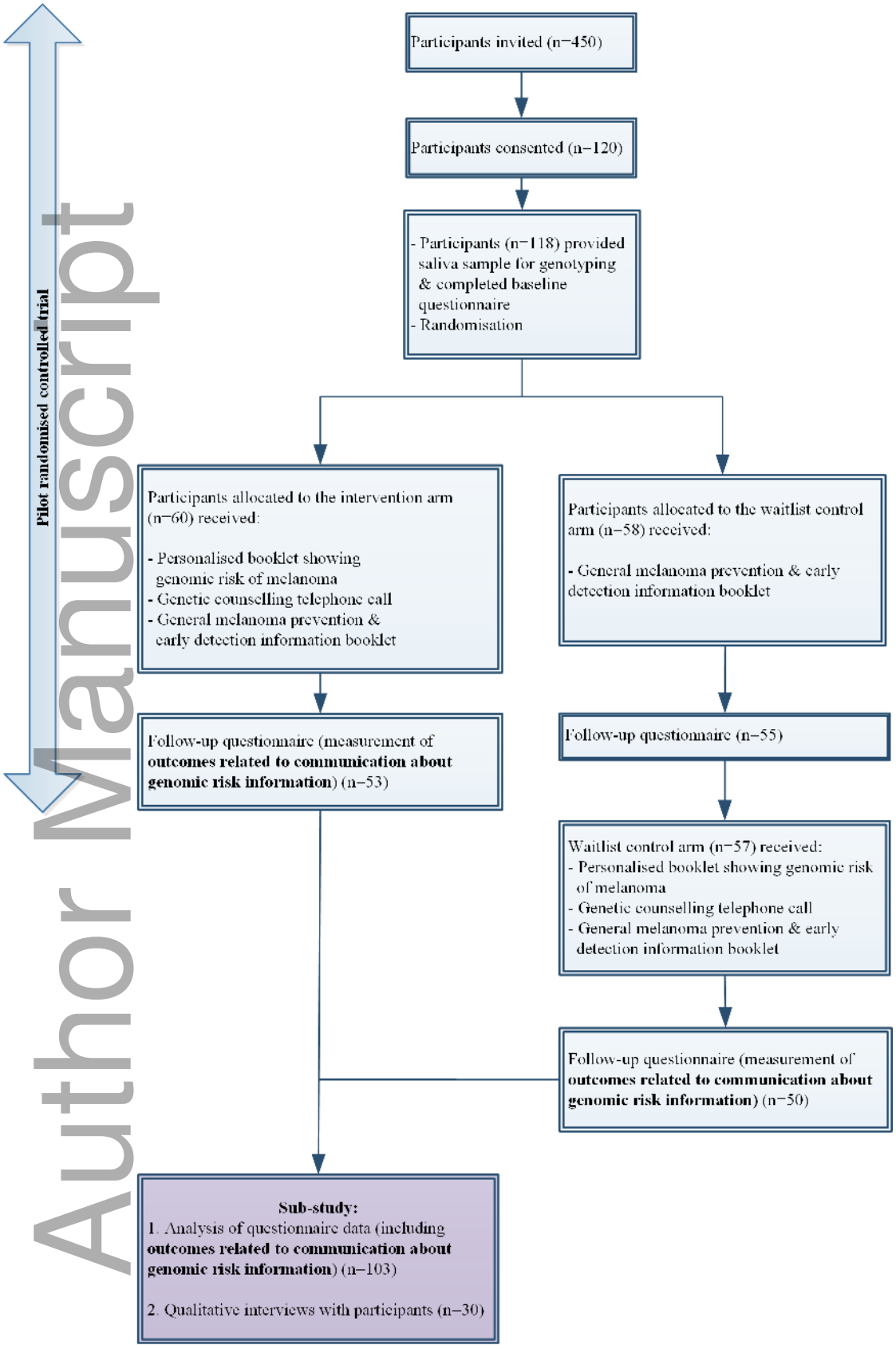
Table 5: Themes describing the content from conversations about melanoma genomic risk

	Themes	Genomic risk (sex, age)	Examples of quotes
Family	Shared risk	high (male, 58)	“Because one of my brothers works on the council, I said, you know you've got to cover up. I said, because we've all got the same DNA, more or less, you know, we've all got the same genes.”
		high (male, 59)	“My brother and sister are both intelligent, well-educated people. I wouldn't need to tell them you ought to be wearing a hat, but what I did say to them was look, I've got this 50 per cent elevated melanoma risk, you almost certainly do too. So I mean the rest of it is presumed knowledge; they suffer the same skin pigmentation that I have all of their lives and they don’t need telling; the slip-slop-slap stuff is well and truly in the psyche if you like.”
		average (female, 24)	“I was saying to some of my immediate family, with my dad, he's quite dark, and to my brother who I guess we have very similar skin, I said, look I thought because of dad being darker, I would have a lower risk, but I just have same sort of risk as anyone else.”
		low (female, 51)	“So just all I remember, when it arrived, it was very helpful, I shared it with my family and I just told them, like thumbs up, we don't have this, at least not from my part, to give it to you. Yeah, basically I understood that it was a good thing for me, yeah.”
	Sun protection	high (female, 64)	“I spoke to my brother and my daughter and that about it, the fact that we've got to be conscious of the melanomas and just keep doing what you're doing with the sun cream and stuff and out in the sun and all that sort of thing.”
		average (female, 63)	“I spoke to my husband about wearing skin protection and a hat, yeah, that sort of stuff and probably my risk.”
		low (female, 38)	“And using it with my children and things like that, because my children have olive skin. I have an 11-year-old who doesn't like sunscreen because it feels greasy and so he won't wear it a lot - he's pretty good, but he's not very good at wearing a hat. So just saying to him, look if we do all these things together then it will help as well.”
Friends	Perception of genetic risk as not a serious issue	high (female, 51)	“I mentioned it to people at work in a sort of fairly light way, but not really”
		low (male, 58)	“Because I didn't see this as a major issue, it was just something that had been done and that was the result of it. I would have said to my friends, have a look at this, this is what's come back and yeah, that would have been the conversation.”
Health Professionals	Advice from GP	high (male, 39)	“I showed him the booklet and he just told me to keep an eye on my skin, let him know if I notice any changes”
		average (female, 45)	“I think it was a useful thing that my genetic risk information was sent to her as well, so it did prompt a conversation between us and it also prompted a skin check, which I had had before, but I don’t know when. So we've now put that, you know, in the reminder system to happen on a more regular basis.”

Table 6: Themes describing the reactions to conversations about melanoma genomic risk information

	Themes	Genomic risk (sex, age)	Examples of quotes
Family	Worry	high (male, 37)	"My wife was probably a little bit worried I suppose in relation to, gosh am I going to be here by myself looking after the kids. Because you know, we had a bit of a rough trot last year with a couple of members of the family passing away and whatnot. I think she's okay because I'm not the sort of person that just goes outside and just sits in the sun. So she knows I'm pretty good in that sense, but we all think that I'm probably less of a risk with all the precautions that I'm doing, yeah."
	Behaviour change	high (female, 30)	"My parents certainly have started being really careful in the sun as well as a result. They used to not worry so much about it, but definitely in the last couple of months they've picked up a little bit more, always got hats with them, always got sunscreen."
		high (male, 66)	"My brother is very happy with the information, because he now wears a hat and wears long sleeves."
		high (male, 69)	"I think the information spurred my wife on to actually get herself checked, which she did."
		average (female, 24)	"My brother went and got his skin checked because he'd never done that and he had quite a few moles"
Friends	Supportive reactions	average (male, 66)	"Now my friend that I used to work with, who has scars all over him now, I told him about it and he just said, well that's great, that's really good, but yeah, we never got into any depth about it."
		low (female, 69)	"Well I think they were pleased that I'd done it and thought I was very lucky to have that concrete information to rely on."
Health professional	No change in care	high (female, 52)	"My GP thought it was interesting and then she referred me to the skin specialist that I see anyway. My skin specialist went, oh right, thank you and it's not going to affect her care, she's just going to thoroughly check me every 12 months. It might be every six months, I can't remember. So I feel like that's good. I don't think it's going to change what she does and she's well aware of my father's medical history, so I guess she's even more vigilant."
	GP	average (male, 66)	"In one my consultations with him, he noted it and he said, I can't quote him, but he basically said, I see you've been involved in this study. He said, that's very good and that's it, end of story, no more, no less, just said, that's very good"

	acknowledgement	low (male, 66)	“I did mention my GP that I was taking part in a melanoma study, but I don’t think there was any particular comment about it. She might have just made a note, but I think I mentioned to her my risk assessment and I think she might have made a note about that, but I don’t think she made any particular comment about it.”



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