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SOCIAL MEDIA USAGE IN FAMILY COMMUNICATION ABOUT GENETIC INFORMATION: "I NO LONGER SPEAK WITH MY SISTER BUT SHE NEEDED TO KNOW"

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ABSTRACT

The use of social media has become a ubiquitous form of communication. Little is known about whether social media is used in families to assist with the communication of genetic information. This study aimed to understand if and why individuals use social media to communicate genetic information to at-risk relatives.

Individuals with either a pathogenic variant in a cancer predisposing gene or a heterozygous pathogenic variant in an autosomal or X-linked recessive gene were surveyed about communicating genetic information to their at-risk relatives and their use of social media to assist this process. Surveys were sent to 323 individuals from a reproductive carrier screening program and 250 individuals from a familial cancer center.

The 128 responses (response rate 25.2%) showed that while most participants (79.0%) did not use social media to communicate genetic information, those that did use social media (21.0%) found it to be helpful as it was easy, accessible and allowed individuals to overcome communication barriers.

Genetic professionals should be aware that social media is being used by individuals to assist family communication about genetic information and should discuss this method of communication with individuals who are faced with communicating genetic information with their family.

Key Words: Social media; family; communication; genetic information; dissemination

INTRODUCTION

Genetic information may have health and reproductive implications for individuals and their families (Bower, McCarthy Veach, Bartels, & LeRoy, 2002; Galvin & Young, 2010; Hodgson et al., 2016; Leonard & Newson, 2010). Family communication can allow at-risk family members the opportunity to make informed decisions about their genetic testing options and subsequent healthcare (L. Forrest, Delatycki, Curnow, Skene, & Aitken, 2010). When a pathogenic variant has been identified in an individual, there is usually a discussion between the genetic health

professional and the person in whom the pathogenic variant has been identified about informing at-risk relatives of the ensuing genetic information (Mendes, Paneque, Sousa, Clarke, & Sequeiros, 2016). However, literature indicates that communication with at-risk relatives is complex and often inadequate (K. Forrest et al., 2003; L. Forrest, Delatycki, Skene, & Aitken, 2007; Gaff, Collins, Symes, & Halliday, 2005; Wiens, Wilson, Honeywell, & Etchegary, 2013) with a significant proportion of family members reporting being unaware of their at-risk status (Sermijn et al., 2004). Individuals can face challenges to communication at a practical level when there is a lack of contact information for relatives or the death of an intervening relative (Healey et al., 2017). Family rifts may also hinder communication within families, resulting in some family members either actively choosing not to disclose information to specific relatives or having difficulty overcoming communication breakdowns (Gaff et al., 2007).

While there is general consensus that it is the responsibility of the individual in the first instance to inform at-risk relatives (Daly, Montgomery, Bingler, & Ruth, 2016; L. Forrest et al., 2007; Gaff et al., 2007; Gaff & Hodgson, 2014) studies have shown there is a need for genetic professionals to act in a supporting role and provide interventions that facilitate effective information sharing (K. Forrest et al., 2003; Gaff & Hodgson, 2014; Sermijn et al., 2004). Such interventions aimed at facilitating dissemination of genetic information to at-risk family members have resulted in increased contact with genetics services by relatives (L. Forrest, Burke, Bacic, & Amor, 2008; Gaff & Hodgson, 2014; Suthers, Armstrong, McCormack, & Trott, 2006). Interventions have included: (i) providing increased counseling support to the consultand during the session and follow up telephone calls to encourage communication to at-risk relatives (L. Forrest et al., 2008); (ii) a specially designed telephone genetic counseling intervention aimed at improving family communication (Hodgson et al., 2016); and (iii) letters written by the genetics service and sent directly to at-risk relatives (Suthers et al., 2006).

Social media

'Social media' is an umbrella term that refers to freely available online platforms that allow the sharing and creation of user generated content (Chretien & Kind, 2013; Gage-Bouchard, LaValley, Mollica, & Beaupin, 2016; Kaplan & Haenlein, 2010). Content can be easily disseminated among a specified group of people or among the wider general population. In recent years, Facebook has become a popular communication platform for many individuals (Chretien & Kind, 2013). Social networking sites typically allow users to privately and instantly message each

other and will often notify users of new messages on their mobile telephones. As such, the messaging functions associated with social networking sites are used alongside standard text messaging functions (Househ, 2011). Social media across a broader healthcare context is being used in many ways by both patients and healthcare professionals, with an increased trend in individuals sharing their own personal health information on social networking sites (Househ, 2011). Househ (2011) found that some Facebook users were posting personal details of their condition (including genetic conditions) to their Facebook 'wall' and to dedicated groups for the condition, and suggests that this behavior may be due to a cultural change in patient engagement and a sense of empowerment from being responsible and in control of their own health.

Currently, there is little literature exploring whether clients and professionals engage with social media in a genetic counseling setting. Moore and colleagues (2018) surveyed full members of the National Society of Genetic Counselors in the USA and Canada and genetics patients in Cleveland about their interest in using social media for patient-provider interaction. The authors found that a majority (67.3%) of genetic counselors were indifferent or not interested in utilizing social media for patient-provider interactions, which contrasted with 54.1% of patients expressing an interest, highlighting a readiness by patients to embrace interactions about genetic information via social media (Moore, Matthews, & Cohen, 2018). Other studies have considered the benefits of social media for promoting profession awareness (Gallagher, McCuaig, Benoit, & Davies, 2016) and for supporting the psychosocial and informational needs of individuals impacted by genetic conditions (Barton, Wingerson, Barzilay, & Tabor, 2018; Stefansdottir, 2016).

While there is an abundance of literature exploring family communication in a genetic counseling context, there is a lack of research exploring the role of social media in the communication process. As modern communication is increasingly occurring online, research is needed to consider the use of social media to communicate genetic information and whether social media platforms can be suggested by genetic professionals as a useful tool for facilitating family communication. Therefore, this study aimed to better understand if and why individuals use social media to communicate genetic information to their at-risk relatives. The outcomes from this research may provide information for genetic professionals to inform practice about the current use of social media by individuals in communicating familial genetic information.

MATERIALS AND METHODS

Participants

Potential participants were identified from two clinical genetics services in Victoria, Australia: the Victorian Clinical Genetics Services' reproductive carrier screening program which screens for carrier status for cystic fibrosis, fragile X syndrome, and spinal muscular atrophy (carrier screening cohort); and the Parkville Familial Cancer Centre at the Peter MacCallum Cancer Centre (cancer cohort). Eligible participants were identified if they were the proband for a cancer predisposing autosomal dominant pathogenic variant or were found to be a carrier of an autosomal recessive or X-linked genetic condition. All potential participants had received genetic testing results between January 2011 and August 2016, were aged over 18 years, and could read and write English.

Recruitment

A total of 573 potential participants were invited to participate, 323 from the carrier screening cohort and 250 individuals from the cancer cohort, in April and May 2017. Potential participants with email addresses available were invited by email that included a link to the online version of the questionnaire. Potential participants invited by post received a hardcopy questionnaire, a reply-paid envelope and the link to the online questionnaire. Participants invited by email were advised to contact the primary researcher if they required a hardcopy questionnaire.

Questionnaire tool

A cross-sectional anonymous questionnaire was purposefully designed based on a review of the literature examining family communication about genetic information and the clinical experience of the research team (Supplementary Material and Methods S1) (Boynton & Greenhalgh, 2004). The questionnaire captured six domains; (i) demographic data, (ii) interactions with genetic professionals, (iii) understanding of the severity of the condition, (iv) disclosure of genetic information, (v) methods of communication of risk to family members, and (vi) reasons for choosing these methods. Responses to questions included single and multiple choice options and free-text responses.

Data management

Study data were collected and managed using REDCap electronic data capture hosted at the Murdoch Children's Research Institute (Harris et al., 2009). Partially completed questionnaires completed via hardcopy and returned using the reply-paid envelope were included in the dataset. It was assumed that because the participants deliberately posted the questionnaire back to the

researchers, they intended for their responses to be included in the study. Partially completed questionnaires submitted online were not included in the dataset to avoid possible duplication if the participant chose to exit and then complete the questionnaire either online or in hardcopy at a later stage.

Data analysis

Quantitative statistical data analysis was performed using STATA Data Analysis and Statistical Software (StataCorp, 2017). Data analysis was predominantly descriptive using numbers and percentages to summarize categorical and multiple-choice responses. Two sample *t* tests were used to assess statistical significance between participant groups and continuous variables (e.g. age). Age distribution was assessed for normality. Statistical significance of between-group comparisons was assessed using Chi-squared tests of association for categorical variables. A p value of <0.05 was considered statistically significant.

Free-text responses were analyzed using inductive content analysis to allow categories and concepts to be derived from the data (Elo & Kyngas, 2008). Coding was performed independently and later reconciled by consensus of two researchers (SL and MAY). The data that support the findings of this study are available from the corresponding author, upon reasonable request.

RESULTS

Data collection was censored on 27 July 2017 with 128 responses and a response rate of 25.2%. Of the 573 invitations, 63 postal invitations (60 carrier screening cohort and 3 cancer cohort) and 2 email invitations to potential cancer cohort participants were undeliverable, leaving a total of 508 potential responses (see **Figure 1)**. Sixty-one participants responded by hardcopy questionnaire (47.4%), while 67 (52.3%) completed the questionnaire online. Participants were predominantly female and the carrier screening respondents (mean age 36.29, *SD* 4.48) were significantly younger than the cancer cohort (mean age 55.86, *SD* 12.80) ($p<0.01$) (see **Table 1)**.

Communication about the genetic condition

From 127 responses, 121 participants (95.3%) reported that they had informed relatives about their risk of carrying the genetic condition. There was evidence of a difference in disclosure rates between the two cohorts, as all participants (69/69, 100%) from the cancer cohort reported informing relatives about the genetic condition as opposed to 52/56 (89.7%) of participants from the carrier screening cohort ($\chi^2(1)= 7.49$, $p= 0.006$).

Social media use

Of the 121 participants that reported communicating to relatives about the risk of the genetic condition, 25 (21.0 %) reported that they had used social media to communicate with their relatives (see **Table 2**). The most frequently used platforms to assist communication were Facebook (19/25, 76.0%) and Facebook messenger (17/25, 68.0%). Other platforms used included Google+ (8/25, 32.0%), Twitter, (2/25, 8.0%), YouTube, (2/25, 8.0%) and WhatsApp (1/25, 4.0%). Participants could select multiple options. Despite the cancer cohort social media users being older (mean age 53.5 years, *SD* 11.17, range 27 – 69) than the carrier screening social media users (mean age 37 years, *SD* 3.39, range 32 – 40), age was not statistically significant between the two groups ($t(118)= 1.12$, $p=0.26$). There were no statistical differences observed between participants who did or did not use social media to communicate genetic information by gender ($\chi^2(1) = 0.68$, $p= 0.40$) or education levels ($\chi^2(4) = 1.47$, $p=0.83$).

Communication methods

Of 96 participants who did not use social media to communicate the genetic condition to their relatives, 77 (80.2%) reported communicating in person or by telephone (69/96, 71.9%). A quarter of participants cited using email as a method of communication (24/96, 25.0%), while participants rarely reported using regular mail to pass on information to relatives (4/96, 4.2%). Using letters provided by the genetics service was seldom reported as a method of communicating genetic information with relatives (10/96, 10.42%). Participants could select multiple options.

Reasons for communication method

Social media

Most participants who used social media reported they found it helpful for communicating genetic information with their relatives (24/25, 96.0%). Additionally, 24 of 25 participants (96.0%) responded that they did not regret using social media to communicate genetic information to their relatives. Most participants who used social media indicated that they did so to communicate with relatives with whom they had an established connection on social media (see **Table 3**).

Free-text responses described other reasons for using social media, including using social media to assist in overcoming communication barriers, such as geographical distance, lack of alternate contact information, or death of a linking relative:

> *"My father has passed and I have no physical contact with my father's side of the family. Social media brought us back together*." (Respondent number 42, cancer cohort, female, age range 45 – 54)

For participants who were estranged from a family member, social media provided a mode of communication that did not require personal contact yet allowed them to discharge their responsibility of informing their at-risk family member:

"I no longer speak with my sister but she needed to know." (Respondent number 68, cancer cohort, male, age range 55 – 64)

Participants also found social media helpful due to its convenience, saying *"It is simple, quick and easy, I could tell multiple relatives at once."* (Respondent number 14, carrier screening cohort, female, age range 25 – 34) and enabled participants to document the content of the communication and record that the information had been received and read:

*"Social media… was immediate communication but also served to keep a record of what was said (written)..." (*Respondent 71, cancer cohort, female, age range 55 – 64)

"It seems easier than text or email, I can write down what I want to say, check it, send it and then can see they have received and read it." (Respondent number 43, cancer cohort, female, age range 45 – 44)

'Traditional' communication methods

More than 80% of participants who did not use social media to communicate genetic information reported that they preferred to communicate this information in person or by telephone, and almost 20% indicated they had not thought of social media as an option for communicating genetic information with relatives (**Table 4**). Free-text responses showed participants regarded social media as inappropriate for discussing genetic information as genetic information was considered too personal, private and serious, and participants were concerned that the information may be misconstrued:

"Social media is quite an impersonal way of communicating. Hearing about the possibility of a genetic condition can be quite shocking, surprising, emotional. I don't believe such information is appropriate to share via social media where messages can be misunderstood or misinterpreted + emotional support cannot be provided as effectively." (Respondent 48, carrier screening cohort, female, age range 35 – 44)

"Not appropriate. Information like that is personal, private and sensitive. Social media is none of those things." (Respondent 77, cancer cohort, female, age range 45 – 54)

Participants also identified a lack of trust toward the privacy and confidentiality of social media:

> *"I don't particularly trust social media sites/platforms with my genetic information & therefore choose not to distribute information through these channels." (*Respondent 84, carrier screening cohort, female, age range 25 – 34)

DISCUSSION

This study found that while family communication about genetic information mostly occurred via traditional methods of communication, individuals did report using social media to communicate with their relatives. Additionally, our results suggest that a diverse demographic of people are utilizing social media as a communication platform, and its uptake does not appear to be limited to younger individuals. This finding is consistent with research conducted by the Pew Research Center's Internet & American Life Project that showed that the use of Facebook among older adults aged 65 and over increased by 14% from 2015 to 2016. Greenwood and colleagues (2016) also identified an overall increase in usage of Facebook by 7% from 2015 to 2016, highlighting a general increasing engagement with social media (Greenwood, Perrin, & Duggan, 2016). It is therefore possible that since this study was undertaken, communication about genetic information via social media has increased. Given the evidence that some people are choosing social media as a platform for disseminating genetic information to their relatives, it is important to consider how best to support these individuals.

Our findings showed that the motivations for those participants who used social media were many and varied. Participants appeared to not only use social media to discuss genetic information with relatives, but also to facilitate information seeking, discuss risk management options and to gain support. These findings support previous studies that have recognized the benefits of social media in providing support to individuals in documenting their health journey, sharing the emotional strain of a diagnosis and for gathering health information (Barton et al., 2018; Gage-Bouchard et al., 2016; Househ, 2011, 2013). The majority of those who used social media considered it helpful for communicating genetic information to their relatives and did not regret their decision to do so. The usefulness of social media for communicating genetic information extended to its accessibility, ease of use and convenience. Having a positive experience in communicating genetic information with a family member has been shown to increase the likelihood of further communication with other relatives (Lafreniere, Bouchard,

Godard, Simard, & Dorval, 2013; Mesters, Ausems, Eichhorn, & Vasen, 2005). For those utilizing social media to communicate genetic information, establishing easy and positive interactions with relatives on social media may therefore provide opportunity and motivation to reach more distant relatives in the future, which can help to achieve the maximum public health benefits of predictive and carrier testing (Healey et al., 2017).

Importantly, participants used social media to assist in overcoming barriers to communication. The communication barriers participants faced in the current study were not unique. One study exploring barriers to dissemination of information among Australians with *BRCA1* and *BRCA2* mutations revealed that the most commonly recorded barrier to family communication was loss of contact (Healey et al., 2017). Loss of contact in Healey and colleagues' (2017) study encompassed situations where there was death of a linking relative, immigration of relatives or a lack of alternate contact information, which are consistent with those described by participants in the current study. While these communication barriers present practical challenges, finding a way to overcome estrangement in order to communicate genetic information can be a source of anxiety (Agllias, 2011). When describing why he found social media to be helpful for communicating genetic information, one cancer cohort participant stated that while he no longer spoke with his sister, he felt his sister needed to know about her genetic risk. For this participant, social media provided an avenue for communication when other more direct methods may have been too difficult. It appears that in this case social media could provide a reasonable alternative to telephone or face-to-face contact when an individual is facing challenges in otherwise communicating with a relative.

The current study highlights that social media is involved in disseminating genetic information to at-risk relatives for some individuals, and this should be considered as an option in clinical settings when discussing how family communication might take place. This is not to say that genetic professionals need to actively encourage social media as a replacement for 'traditional' communication methods. Indeed, our findings suggest that despite the increasing intergration of social media into everday communication behaviours (Mihailidis, 2014; Sago, 2013), family communication of genetic information continues to be grounded in a preference for traditional methods of communication. A study conducted by Mihailidis and colleagues (2014) found that while half of their participants were 'friends' with their parents on Facebook, family communication was still most commonly undertaken by telephone. Furthermore, respondents

emphasized that social media may be perceived as inappropriate for family communication about 'serious' and 'personal' genetic information and that it can limit one's ability to effectively guage family members' reactions and provide real-time support. An advantage of face-to-face communication is that it conveys verbal, non-verbal and social context cues simultaneously, which provides the opportunity for immediate and synchronized feedback (Wang et al., 2015). It is likely that social media might never play a role in family communication about genetic information for those with established family communication patterns founded on traditional methods. However, for those who may wish to simply deliver the information to discharge their responsibility to inform at-risk family members without engaging in emotional or personal conversations, social media provides a unique platform to undertake this communication.

Findings from the current study underscore the importance of aligning with a client and family-centered approach when working with individuals to facilitate meaningful family dialogue (Daly, 2015). It is important that genetic professionals empower individuals to communicate to their at-risk family members in a manner that is underpinned by their preferences and practical circumstances. It may be that some people use social media as a bridging tool to gather telephone numbers or email addresses of family members they are not otherwise in contact with, while others could feel comfortable initiating a conversation about genetic risk over a private message. Additionally, the privacy concerns expressed by some participants should not be ignored. The finding that some participants did not trust social media with their private and confidential genetic information is supported by existing literature. A study by Antheunis and colleagues (2013) investigating patients' and health professionals' motives and use of social media for health-related reasons found that the main barrier for social media use by patients resulted from privacy concerns. These concerns about online privacy suggest a need for an explicit conversation with individuals considering using social media about their level of comfort with such privacy issues.

Interestingly, our study revealed a limited use of letters provided by the genetic service in assisting family communication, although it is possible that a family letter was not provided to all participants. Studies have shown individuals often perceive communication about genetic information with their relatives as their responsibility and not that of the genetics service (K. Forrest et al., 2003; L. Forrest et al., 2008; Gaff et al., 2005; Hallowell et al., 2005). Family letters are often written using formal language, which may result in a lack of connection by the client toward the language used to describe the condition in their family. Consequently, individuals may

perceive a loss of ownership over the information detailed in the letter, which may cause hesitation in the distribution process. Participants in this study were not asked why they did not use the family letter more frequently, however, considering the high reported rate of disclosure, respondents may not have felt the need to rely on a letter from the genetics service, to inform at-risk relatives about familial genetic information.

Research recommendations

While this study highlighted a positive experience of those who used social media to communicate genetic information to their relatives, further research is needed to gain an understanding of the views of individuals who have been informed that they are at risk of a genetic condition by social media. If the experiences of those who receive information this way are negative, it would change the advice health professionals might provide people about the use of social media for communication. Additionally, this study did not account for the impact that an individual's ethnicity or cultural background may have on their decision to utilize social media to communicate genetic information. Future studies may explore whether cultural influences encourage or deter individuals from using social media to communicate genetic information with relatives.

Study limitations

There are several limitations with the current study. The overall response rate of 25.2% for this study is relatively low. A higher response rate would have been desirable to reduce possible differences in the use and views of social media between those who did and did not respond to the questionnaire. Additionally, there was potential for recruitment bias in that individuals who have an interest in family communication or social media may have been more likely to respond than those who were unconcerned about those topics. Due to the participant demographic being predominantly female, it is not clear if and how males use social media to communicate genetic information. The response rate and skewed demographics therefore caution that the findings may not be representative of and generalizable to broader cohorts. The fact that some participants received results as far back as six years ago may have resulted in them not accurately recalling how they shared the genetic information in their family. In addition, as social media has become more commonly used over this period, it is possible that this may result in more people using social media to disseminate information since that time. This study provides a baseline insight about whether individuals use social media to communicate genetic information with their relatives and

their reasons for doing so. However, this study would have benefited from further questions delineating methods of information sharing as it is recognized that there are inherent differences between posting genetic information to one's Facebook wall and sharing information via a private Facebook message. In addition to asking participants if they used social media and what platforms they engaged with, future studies could include questions to elicit specific methods of communication via social media platforms.

Practice implications and conclusion

Like previous studies, this study has once again revealed the complexity of family communication (Dancyger et al., 2011; K. Forrest et al., 2003; Gaff et al., 2007). Families are diverse and varied, and the communication techniques utilized by one family may not be practical for the next. It is crucial that genetic professionals continue to work closely with individuals and families to both discuss how communication might take place and how potential barriers might be overcome. Our findings suggest that in certain circumstances, social media may provide a useful family communication resource, particularly when there are barriers to communication. Genetic professionals should therefore consider the inclusion of discussion about the role of social media in family communication in their genetic counseling toolkit.

AUTHOR CONTRIBUTIONS

Elly Lynch was responsible for the conception of the research idea and all authors contributed substantially to the design of this study. Sarah Leighton was solely responsible for the acquisition, management and statistical analysis of data. All authors contributed to the interpretation of data. Sarah Leighton wrote the original manuscript draft and all authors were involved with the revision and editing of the manuscript. All authors agree to be accountable for all aspects of the work and ensuring that questions related to the accuracy and integrity of the work are appropriately investigated and resolved.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

HUMAN STUDIES AND INFORMED CONSENT

Human research ethics committee approval was obtained from the Royal Children's Hospital Ethics Committee on 16 March 2017 and governance approval was provided by the Peter MacCallum Cancer Centre Ethics Committee on 21 March 2017. All participants were provided with a 'participant information statement' and informed consent was implied upon return of the questionnaire.

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FIGURE LEGENDS

Figure 1. Outcome of recruitment of participants, administration of questionnaire and response rate for the carrier screening cohort and the cancer cohort

[a]Study total is greater than combined total for the two participant groups as a participant group was unknown for one participant

Table 1. Comparison of participant demographic information according to participant group

Variable	Cohort		Study total	*P* value
	Carrier screening n= 58 n (%)	Cancer n= 69 n (%)	n= 128 n (%)	
Gender				0.1*
Female	55 (94.8)	59 (85.5)	114 (89.1)	
Male	3 (5.2)	9 (13.0)	12 (9.4)	
Unknown	–	1 (1.5)	2 (1.5)	
Age in years				<0.01**
Mean (range); *SD*	36.29 (28-50); 4.48	55.86 (27-88); 12.80	46.85 (27-88); 13.89	
25-34	21 (36.2)	5 (7.3)	26 (20.3)	
35-44	33 (56.9)	8 (11.6)	41 (32.0)	
45-54	4 (6.9)	18 (26.1)	22 (17.2)	
55-64	0 (0.0)	20 (29.0)	20 (15.6)	
65-74	0 (0.0)	12 (17.4)	12 (9.4)	
75 and over	0 (0.0)	5 (7.3)	5 (3.9)	
Unknown	–	1 (1.5)	2 (1.6)	
Genetic condition				–
Cystic fibrosis	32 (55.17)	–	32 (25.0)	
Fragile X syndrome	1 (1.72)	–	1 (0.8)	
SMA[a]	21 (36.21)	–	21 (16.4)	
Lynch syndrome	–	20 (29.0)	20 (15.6)	
HBOC[b]	–	41 (59.4)	41 (32.0)	
Other inherited cancer[c]	–	8 (11.6)	8 (6.3)	
Not sure / do not remember	4 (6.9)	0 (0.00)	4 (3.1)	
Unknown	–	–	1 (0.8)	
Highest level of formal education				<0.01***
Did not complete secondary school	0 (0.0)	13 (18.8)	13 (10.2)	
Completed secondary school	4 (6.9)	9 (13.0)	13 (10.2)	
Certificate or TAFE[d]	8 (13.8)	17 (24.6)	25 (19.5)	
Bachelor degree	17 (29.3)	15 (21.7)	32 (25.0)	

Postgraduate	29 (50.0)	14 (20.3)	43 (33.6)
Unknown	–	1 (1.5)	2 (1.5)

Note: 'n' represents the number of actual responses provided, as not all questions were answered by all participants

[a]Spinal muscular atrophy [b]Hereditary breast and ovarian cancer

[c]Other inherited cancer genes included *TP53, MEN1, PALB2, SDHB* and SDHD

[d]Technical and further education

*p value calculated with the Pearson χ^2 test with one degree of freedom

**p value calculated with a two-sample t test

***p value calculated with the Pearson χ^2 test with four degrees of freedom

Table 2. Comparison of the use of social media to communicate genetic information between participant groups

Question	Cohort		Study Total	*P* value*
	Carrier screening n= 52 n (%)	Cancer n=69 n (%)	n= 121 n (%)	
Have you used social media to communicate genetic information about the genetic condition to your relatives?				
Yes	5 (9.6)	20 (29.0)	25 (21.0)	<0.01
No	47 (90.4)	49 (71.0)	96 (79.0)	

**p* value calculated with the Pearson χ^2 test with one degree of freedom

Table 3. Reasons participants used social media to communicate genetic information with their relatives

Question	Cohort		Response total
	Carrier screening n= 5 n (%)	Cancer n= 20 n (%)	n= 25 n (%)
What are the reasons you used social media to assist your communication about genetic information with your relatives? [a]			
Getting in contact with a relative I am already connected with via social media	5 (100.0)	16 (80.0)	21 (84.0)
To seek or gather information about the genetic condition	1 (20.0)	10 (50.0)	11 (44.0)
To seek or gather information about the health of relative	1 (20.0)	8 (40.0)	9 (36.0)
To discuss risk management	1 (20.0)	7 (35.0)	8 (32.0)
For support	0 (0.0)	8 (40.0)	8 (32.0)
To ask other family members about how to communicate to my relatives	1 (20.0)	5 (25.0)	6 (24.0)
Searching for a relative I am not in contact with in daily life	0 (0.0)	6 (30.0)	6 (24.0)
Other, please specify	2 (40.0)	3 (15.0)	5 (20.0)
I prefer to interact with that relative on social media rather than in person or on the phone	0 (0.0)	3 (15.0)	3 (12.0)

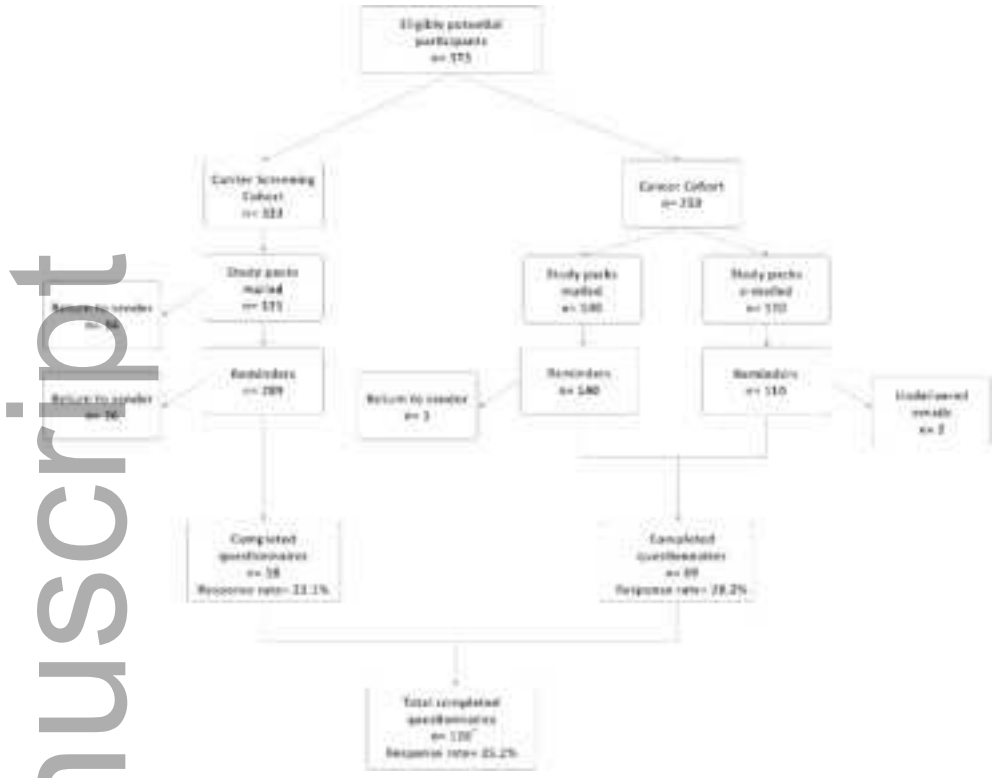
Note: 'n' represents the number of actual responses provided, as not all questions were answered by all participants.
[a]Participants could select multiple responses. Therefore, the total percentages next to each option do not equal 100%

Table 4. Reasons participants did not use social media to communicate genetic information with their relatives

Reason[a]	Cohort		Response total
	Carrier screening n= 47 n= (%)	Cancer n= 49 n= (%)	n= 96 n= (%)
Prefers to communicate genetic information in person or on the telephone	38 (80.9)	41 (83.7)	79 (82.3)
Did not think of social media as an option	9 (19.1)	10 (20.4)	19 (19.8)
Does not use social media	2 (4.3)	12 (24.5)	14 (14.6)
Relatives do not use social media	7 (14.9)	6 (12.2)	13 (13.5)
Other, please specify	8 (17.0)	3 (6.1)	11 (11.5)
Prefers to communicate genetic information via letters or post	2 (4.3)	8 (16.3)	10 (10.4)

Note: 'n' represents the number of actual responses provided, as not all questions were answered by all participants.

[a]Participants could select multiple responses. Therefore, the total percentages next to each option do not equal 100%



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