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Information-Seeking and Sharing Behavior Following Genomic Testing for Diabetes Risk

Rachel Mills^{*}, Jill Powell, William Barry, and Susanne B. Haga

Duke Institute for Genome Sciences & Policy Duke University

Abstract

As the practice of medicine has become more patient-driven, patients are increasingly seeking health information within and outside of their doctor's office. Patients looking for information and support are often turning to the Internet as well as family and friends. As part of a study to understand the impact of delivery method of genomic testing for type 2 diabetes risk on comprehension and health-related behaviors, we assessed participants' information-seeking and sharing behaviors after receiving their results in-person with a genetic counselor or online through the testing company's website. We found that 32.6% of participants sought information after receiving the genomic test results for T2DM; 80.8% of those that did seek information turned to the Internet. Eighty-eight percent of participants reported that they shared their T2DM risk results, primarily with their spouse/partner (65%) and other family members (57%) and children (19%); 14% reported sharing results with their health provider. Sharing was significantly increased in those who received results in-person from the genetic counselor ($p=0.0001$). Understanding patients' interests and needs for additional information after genomic testing and with whom they share details of their health is important as more information and clinical services are available and accessed outside the clinician's office. Genetic counselors' expertise and experience in creating educational materials and promoting sharing of genetic information can facilitate patient engagement and education.

Introduction

Due to increased patient engagement in health care, information-seeking and sharing have become important components of patients' experiences. Health information-seeking can improve patient engagement, awareness, and empowerment (Lemire et al. 2008). Patients may seek health information for different reasons and at different stages of care, such as prior to a visit to their health provider to learn about potential causes/diagnoses of a symptom, as well as after a health care visit to better understand their diagnosis, treatments, test results, or follow-up recommended by the provider. The widespread and convenient

^{*}Corresponding Author: Institute for Genome Sciences & Policy, Duke University, 304 Research Drive, Box 90141, Durham, NC 27708, Tel: 919.684.2569, Fax: 919.613.6448 r.mills@duke.edu.

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

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access to the Internet (Horrigan and Rainie 2002), as well as availability of health information online has made the Internet the top choice of information-seekers (Park et al. 2009; Fox 2011; Fox and Duggan 2013).

Several factors may impede patients' ability to effectively comprehend and apply information found. For example, information may be written at an inappropriate reading level (Lachance et al. 2010), limiting individuals' understanding of genetic terms and concepts. Furthermore, low health literacy and/or numeracy skills may significantly limit understanding of the information, potentially resulting in poorly informed choices, anxiety, and unnecessary medical treatment (Emslie et al. 2003; Lanie et al. 2004; Christensen et al. 2010; Lea et al. 2011). With implementation of electronic medical records in many practices, patients may be able to access their test report through a patient portal linked prior to being contacted by the provider. This report may be challenging to understand, potentially leading to anxiety and confusion until the provider has an opportunity to discuss the test report with the patient. In addition to concerns about individuals' ability to comprehend information found, there are concerns about quality of information, conflicting information, and the risk for "information overload," potentially leading to confusion, frustration, and poor decision-making (Zeng et al. 2004; Viswanath 2005; Ye 2011; Zulman et al. 2011). Trust in the information is also a concern (Hesse et al. 2005), particularly with information found online (Zulman et al. 2011).

If patients struggle to understand information found or lack credibility in the source, they may turn to other resources such as their physician, family or friends for information and support; others may even access online social networking or patient groups of those affected with the same condition (Frost and Massagli 2008; Zhang et al. 2013). In the process of soliciting information from different people, the individual will likely share some personal health information. Sharing of genetic (and now genomic) test results has been an ongoing interest in the genetics community. Particularly for test results obtained through a DTC company, individuals may share their results with their provider to obtain further information about the significance of the result for their health (Bloss et al. 2013; Darst et al. 2013). For tests ordered by a provider in a clinic setting, patients are likely to share results with family members for social support and family planning (Stoffel et al. 2008; Ashida et al. 2010).

As part of a larger study with the primary goal of understanding the impact of delivery of results for genomic risk testing for type 2 diabetes mellitus (T2DM) on comprehension and health-related behaviors (in-person with a genetic counselor versus online), we also assessed participants' information-seeking and sharing. In particular, we were interested in understanding whether participants sought additional information following testing, where they searched for this information, the ease with which they were able to obtain further information related to genetic testing or T2DM, and whether they shared their results and with whom. Differences in information-seeking and sharing between the study arms that reviewed test results online or in-person with a genetic counselor were also explored. In this paper, we review the findings associated with participant information-seeking and sharing; other findings will be published separately.

Methods

As previously reported (Haga et al. 2013; Mills et al. 2013), 300 participants from the general population of Durham, NC were enrolled in a randomized clinical study on genomic risk assessment for T2DM using recruitment methods such as advertising in newspapers, on public transportation, and online. The primary goal of the study was to assess the impact of the delivery approach (in-person with a genetic counselor or online through the testing company's website) of genomic risk testing results for T2DM on risk comprehension and the impact of learning one's risk on health behaviors. Secondary goals were to explore and understand participant information-seeking and sharing of results; this paper focuses on those secondary goals.

Participants first met with the research coordinator (who is also a genetic counselor) to complete a baseline survey and provide a cheek swab to be used for genetic testing. During that appointment, the research coordinator briefly discussed T2DM and genetic testing with each participant and provided a packet of printed materials (NIH 2006; NDIC 2007). Genotyping was performed in a CLIA-certified laboratory by deCODE, Inc; analysis of *TCF7L2* was conducted in all individuals, *CDKAL1* and *CDKN2A/B* in Caucasian and Asian individuals, and *PPARG* in Caucasians only. Following the completion of testing, participants were randomized to review their test results online through a password-protected site (n=149) or in-person with a genetic counselor (n=151). Test results included the participant's risk of developing T2DM as a relative risk and lifetime percentage risk. Both types of risk information were presented as a number, text, and a graphic (Figure 1). Additionally, result reports and the website included background information about T2DM and the genes that were tested, risk factors for T2DM, a glossary of terms, and references. Participants were required to complete an initial survey prior to testing (baseline) and three follow-up surveys at 1-week, 3-months, and 6-months after receipt of their test results.

Survey Instruments

We assessed general health information-seeking ability and behaviors at baseline using questions from the Health Information National Trends Survey (HINTS)(Nelson et al. 2004) developed by the National Cancer Institute to assess how participants find, use and understand health information (<http://hints.cancer.gov> last accessed 12/5/13). The HINTS survey has been shown to be a reliable measure of information-seeking behaviors/experiences (Nelson et al. 2004). Specifically, the survey includes questions about health information seeking habits, what resources were used when seeking information (i.e., books, internet, health care providers), and experience with seeking information (i.e., did it take a lot of effort to get information, did you feel frustrated during your search). Using questions from this validated survey instrument, we assessed general health-information seeking behaviors prior to testing then specifically regarding their search for health information about the test results or T2DM at 1-week and 3-months following receipt of test results.

As Internet use may affect attitude on receiving genetic testing results online and information-seeking behavior, we assessed participants' Internet usage habits. A single question was created to determine average weekly Internet use: "How much time, on average, do you spend on the internet each week (not work-related)?" This can include time

spent on social networking sites (like Facebook or MySpace), checking personal email, reading blogs, or looking up any sort of information.” Participants’ skills using information technology were also assessed at baseline with the eHealth literacy Scale (eHEALS), an 8-item measure to assess knowledge, comfort, and perceived skills at finding, evaluating and applying electronic health information to health problems (Norman and Skinner 2006). The widely-used instrument has been shown to be reliable and valid in other populations (Norman and Skinner 2006), though one paper suggests that further assessment may be warranted regarding validity of the tool (van der Vaart et al. 2011).

We included a question in each follow-up surveys (1-week, 3-months, 6-months) about whom they had shared their test results (“With whom have you shared your test results?”).

Statistical Analysis

eHEALS scores were summed and tested with the Kruskal-Wallis test, which is a nonparametric version of the one-way ANOVA. Pearson chi-squared tests were used to test for associations in categorical responses. Agreement in subject responses at 1-week and 3-months was evaluated using Cohen’s kappa statistic, and directional changes were assessed using Wilcoxon signed rank test for ordinal scales and McNemar’s test for binary responses. Two-sided p-values and a threshold of 0.05 were used to determine statistical significance.

Results

Participant characteristics

Most participants were female (70%), self-identified as White (60%), and reported a college degree or higher (65%) (Haga et al. 2013). Forty-four percent of participants were between 20 and 29 years of age. Seventy percent indicated that they had a family history of T2DM. After receiving their genomic risk results for T2DM, 254 of the 300 (86%) enrolled participants completed the 1-week follow-up survey; 239 of the 300 (80%) participants completed the 3-month follow-up survey (Table 1). The median range of non-work Internet usage was 8–15 hours per week (26.7%, n=80), with 25% (n=75) spending more than 15 hours per week online.

Participants’ eHEALS scores ranged from 10 to 40 (higher scores indicated greater comfort and skill with electronic health information), with an average of 31.9 (median: 32) (Table 2). Higher eHEALS scores were associated with younger age ($p<0.001$), but not average weekly time spent on Internet ($p=0.33$), or education level ($p=0.59$). Of the eight questions in the eHEALS measure, the question regarding knowledge of how to find helpful health resources on the Internet scored the highest mean confidence level. Participants expressed the least confidence with the statement “I feel confident using information from the Internet to make health decisions.”

Baseline General Health-Information Seeking Behaviors

Prior to testing, the majority of participants (92.3%, n=277) indicated they had looked up information about health or medical topics at some point (Table 1). More than half of participants reported looking up health information for him/herself (58.8%, n=163) and less

than a quarter of participants reporting looking up information for someone else. Health information-seekers indicated that the Internet was their primary resource (81.2%, n=222). Participants whose education status was college or higher and self-reported as White were more likely to report using the Internet for health-information seeking ($p=0.006$ and $p<0.001$, respectively). Of those that used the Internet as a primary resource, 25.7% accessed websites from hospitals and health centers, 19.8% from nonprofit or support organizations, and 18.5% from government health agencies (Table 1).

When searching for health information, few participants believed it took a lot of effort to get the information they sought (13.7%, n=38) or felt frustrated during their search (10.5%, n=29) (Table 3). Most participants reported feeling neutral (42.67%, n=128) or somewhat trusting (44.67%, n=134) of Internet sources, and a smaller proportion expressed concern about the quality of the information (33.6%, n=93). Very few indicated that they had difficulty understanding the information they found (3.2%, n=9).

Post-Testing Information-Seeking Behaviors

At the 1-week follow-up, 22% of participants reported that they had looked for information about health or medical topics related to their test results after receiving their results. At the 3-month follow-up, a significantly higher proportion of participants (32.6%) reported looking for information ($p=0.0005$). At both the 1-week and 3-month follow-up, the Internet was the primary source of information (76.4% and 80.8%, respectively). When asked what specific type of web-site was accessed at the 1-week follow-up, 42.8% reported looking at a website for a hospital or health center. A total of 48% of respondents indicated that they did not have any concerns about the quality of information of that they found compared to 18% who indicated concerns about quality. Sixty-four percent did not report difficulty with understanding the information found compared to 14% that reported difficulty.

At the 1-week follow-up, the proportion of participants that looked for health information was greater in those who received their test results online compared to those who received their results in-person with the genetic counselor, though not statistically significant (27% vs 17%, $p=0.10$). No significant difference was observed in the proportion of participants with increased genetic risk (relative risk higher than 1.10) who sought health information, as compared to others (24% vs. 21%, $p=0.5144$). In addition, no significant difference was observed in the proportion of participants who sought health information with a positive family history as compared to those without a family history ($p=0.43$). eHEALS literacy scores did not vary between participants that did or did not look for health information ($p=0.52$).

Sharing of Results

When asked if participants had shared their test results with anyone 1-week after receiving the results, 74% indicated that they had shared their test results. Of those who had shared the results, 65% shared the results with their spouse/partner and 46% with family members (siblings, parents, grandparents, aunt/uncle, cousins, etc.), 41% with a close friend, 16% with their children, 13% with a co-worker, and 6% with their doctor. A significantly higher proportion of participants who received their results in-person from a genetic counselor

reported sharing their results compared to those who received their results online (55% vs. 45%, $p=0.0001$). However, there was no difference in overall rate of sharing among participants with varying genomic risk (increased, decreased, or population risk) ($p = 0.90$), nor for gender ($p=0.26$).

Similarly, at 3-months, respondents who received their results in-person were more likely to have reported sharing of results than those who received their results online (89% vs. 76%; $p=0.0167$). Of those who shared the results, 65% shared the results with their spouse/partner and 57% with family members, 39% with a close friend, 19% with their children, 15% with a coworker, and 14% with their doctor. At 6-months, respondents who received their results in-person were more likely to have reported sharing of results than those who received their results online (89% vs. 70%; $p=0.001073$).

Discussion

With the increasing development of clinical genetic and genomic tests for a range of conditions, we anticipate a growing demand for patient resources. A better understanding of patient behaviors regarding information-seeking and sharing may help inform development of such resources to meet patient demands. We asked participants' to report their information-seeking and sharing behaviors following receipt of genome risk results for T2DM. We found that the majority of participants did not seek additional health information after receiving their test results. However, most participants reported sharing their results with others. Participants who received their results online did not any show any significant difference with respect to information-seeking compared to those receiving their results in-person with the genetic counselor. But a significant difference in sharing was observed with those receiving their test results from the genetic counselor more likely to share the results with others.

Information seeking

Searching for health information has become a common practice for patients for a wide range of medical conditions and purposes (Tuffrey and Finlay 2002; Boston et al. 2005; Neelapala et al. 2008; van Uden-Kraan et al. 2009; Kim and Kwon 2010; Siliquini et al. 2011). General online health-information seeking behavior will likely continue to grow with the rapidly increasing growth of mobile health applications, increased access to personal health information through electronic medical records and health portals, and availability of online health services. Public misunderstanding of genetic test results purchased and received online has been a major concern about DTC testing companies (Caulfield and McGuire 2012). Although one of the major providers of DTC testing, 23andMe is not currently providing health testing services (FDA 2013), the future of this business for provision of personal genomic information remains unclear.

Although most participants reported seeking health information in the past, only 22% of participants reported searching for health information one week after receiving their test results, increasing to 32% at 3-months post-testing. This low rate of information-seeking may be due to several reasons, particularly the high number of participants with a family history of T2DM (70%). Participants with family history of disease may be more

knowledgeable about the disease and their risk of the disease (Montgomery et al. 2003; M. C. S. Wong et al. 2013), which may explain why no significant difference in information-seeking was observed between those with a family history and those without. Our study population's high levels of genetic knowledge prior to testing may have also accounted for the low level of information-seeking, as those more knowledgeable would be less likely to seek additional information (Haga et al. 2013). Educational materials about genetics and T2DM and general information about testing provided by the research coordinator and genetic counselor at the beginning of the study may have provided sufficient information for participants. Lastly, as there have been questions and concerns about the clinical utility or usefulness of genomic risk for common diseases like T2DM (EGAPP 2007; Prudente et al. 2012; Palomaki et al. 2013), participants may not have perceived the results as significant for their health, and thus, did not warrant seeking additional information. Our study population's high e-health literacy, experience and reported ease with finding online health information in the past makes it unlikely they would have had difficulty searching for additional information if desired.

We anticipated that participants receiving their test result online would have been more likely to search for health information given its convenient access than those that received their results in-person; however, no significant difference was observed. A number of resources were available within the testing laboratory's website, and participants in the online arm may have utilized those resources but did not report it as information-seeking. Likewise, participants who reviewed the test results in-person may have had their questions answered by the genetic counselor, resulting in less need to seek further information.

Not surprisingly, those that did seek health information after receiving their test results turned to the Internet. Participants raised some concern about the credibility of the information they found, especially about the quality of and trust in the information found on the Internet, comporting with other findings (Eysenbach et al. 2002; Arora et al. 2008; Zulman et al. 2011; Ahmed et al. 2012; Miller and Bell 2012; L. M. Wong et al. 2013).

Information sharing

Similar to our population, Fox (2011) reported that 55% of respondents received information or support from their friends and family; however, more of that population (71%) consulted their physician. Patients have reported that they medically benefitted from sharing health information with others, including family and friends (Fox 2013). For heritable conditions, sharing of genetic testing results is common (Wagner Costalas et al. 2003; Stoffel et al. 2008) and may be considered an obligation due to familial implications (Lehmann et al. 2000; Plantinga et al. 2003). Health information-sharing has become more prevalent via social networking sites and online communities (Frost and Massagli 2008; Fox 2011).

The number of participants who shared their results with a health provider was much smaller than reported in a study of DTC testing (Bloss et al. 2013); potentially due to the longer follow-up period (1 year) and multiple disease risks disclosed in that study (28 total) in addition to T2DM. In both studies, genomic risk was not associated with likelihood of sharing (Darst et al. 2013). This is of some concern as it indicates people at increased risk who could benefit the most from preventive interventions are not sharing this information

with providers. In our study population, sharing was associated with receiving results from a genetic counselor. Increased likelihood of sharing genetic information has been associated with genetic counseling intervention (Forrest et al. 2008) and it is common for genetic counselors to discuss implications of genetic test results for family members and encourage sharing.

Study Limitations

Some limitations of this study should be noted. Our study population's higher education level may limit the generalization of our findings to a broader population. The high percentage of health-information seekers using the Internet may be due to the study eligibility requirement that all participants have Internet access, potentially also accounting for the relatively high e-health literacy scores and reported ease in finding and understanding online resources. In addition, the high rate of family history may have biased our results with respect to information-seeking due to higher awareness about T2DM in general. Information-seeking behaviors may have been affected by participants' interactions with the genetic counselor, reducing the need to seek additional information. Likewise, participants may have used the information provided at the beginning of the study about T2DM and genetic testing to answer their questions but did not report it as 'information-seeking.'

Additional research with a more diverse participant group with greater variability in education and internet-use is warranted to confirm our findings. Further analysis of what types of information people sought, which may differ depending on test purpose, patient population, and clinical context, could better inform development of new patient resources or informational websites.

Conclusions and Practice Implications

If patients are to be empowered by knowledge of their genetic risks and encouraged to take preventive steps to minimize disease risks, it is crucial that they are able to understand and process this information appropriately. Genetic counselors will have an important role in the development and sharing of accurate and understandable genetic health information; as more patients will be offered testing or purchase tests on their own, genetic counselors' role will be critical with the expansion of personalized medicine. Although the majority of our study population did not seek further health information after learning of their genomic risk for T2DM, those that did turned to the Internet. Given the increased interconnectivity between general information-seeking and targeted information-seeking for specific clinical information such as interpreting genomic risk for a given condition, genetic counselors, other health providers and laboratories may work together to develop or review such information resources. As genetic counselors are knowledgeable and skilled in promoting understanding about genetic testing and discussing results, their expertise is invaluable in the creation of patient education materials. For example, standard genetic counseling typically includes a discussion of the implications of test results for family members and thus, the importance of sharing these results. However, this is a detail that may be overlooked by other healthcare providers. Therefore, in the development of educational materials, and in the provision of these resources, genetic counselors should emphasize the importance of

sharing results and/or educational materials with family members and other healthcare providers.

In addition, as is current standard practice for genetic counselors, counselors can direct patients to authoritative and accurate online resources for those soliciting additional information during a counseling session, thereby reducing challenges with identifying reliable sources and improving patient-provider communication and decision-making. If a genetic counselor is not directly involved with a given patient's care, they may assist other providers by directing them to helpful patient resources.

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YOUR RESULTS

Type 2 diabetes (T2D) (also called non-insulin dependent diabetes mellitus or adult-onset diabetes) is the most common form of diabetes.

RELATIVE GENETIC RISK

1.10

According to the selected literature, the relative genetic risk calculated from your genotype for males of european ancestry is 1.10. This corresponds to a 27.6% lifetime risk of developing type 2 diabetes, which is 10% greater than for males of european ancestry in general. Note that these calculations may not include all risk factors.

LIFETIME RISK ESTIMATE

27.6%**The lifetime risk of your type**

It is estimated that 28 of every 100 males of european ancestry with your genotype variants develop this disease in their lifetime.

The average lifetime risk

On average, about 25 of every 100 males of european ancestry develop this disease in their lifetime.

Scientific details

Locus	SNP	Genotype Results	Relative Risk	Population Frequency	Cases/Controls
TCF7L2	rs7903146	CT	1.12	0.40	14,586/17,968
PPARG	rs1801282	CC	1.03	0.81	14,586/17,968
CDKAL1	rs7756992	AA	0.90	0.55	3,836/12,562
CDKN2A / B	rs10811661	TT	1.06	0.69	14,586/17,968
Combined relative genetic risk			1.10		
This patient's lifetime risk estimate			27.6%		
General population lifetime risk			25.0%		

These are the results of calculations comparing your genetic sequence to sequence of participants in studies published in the world literature on genetic risk for this disease.

Population risk distribution refers to the risk distribution in the population of european ancestry relative to your risk, i.e. the proportion of individuals who have lower, equal or higher risk than you. The intersection of the red bar with the x-axis, gives the proportion of the population that has greater or lower risk than you.

These are the results of calculations comparing your genetic sequence to sequence of participants in studies published in the world literature on genetic risk for this disease.

Figure 1.

Results included in the test report and on the results website.

Table 1

Participants' Reported Health Information Resources (percentage/actual number).

	Baseline (n=300)	1-Week Post- testing (n=254)	3-Month Post- testing (n=239)
Searched for health information	General health- information seeking	Health-information seeking behavior related to T2DM genomic risk result	
	92.3% (277)	22% (56)	32.6% (78)
Primary Resource for Health Information:			
Printed Materials [Books, brochures, pamphlets, library, magazines, newspapers]	6.8% (19)	5.4% (3)	6.4% (5)
Disease organization	0.72% (2)	1.8% (1)	5.1% (4)
Family, friend, or co-worker	4.7% (13)	9.1% (5)	7.8% (6)
Doctor or healthcare provider	4.0% (11)	7.3% (4)	0% (0)
Internet	81.2% (222)	76.4% (42)	80.8% (63)
• Government health agency	18.5% (41)	21.4% (9)	23.8% (15)
• Hospital or health center website	25.7% (57)	42.8% (18)	23.8% (15)
• Non-profit/support organizations web-site	19.8% (44)	9.5% (4)	9.5% (6)
• Personal blogs or other website	3.2% (7)	9.5% (4)	9.5% (6)
• Don't know/don't remember	19.4% (43)	7.1% (3)	31.7% (20)
• Other	13.5% (30)	9.5% (4)	1.6% (1)
Other	2.2% (6)	0% (0)	0% (0)

Table 2

Responses to e-HEALS questionnaire.

Statement	Strongly disagree/ Disagree	Undecided	Strongly Agree/ Agree	Mean	Median
I know what health resources are available on the Internet	26 (8.7%)	38 (12.7%)	236 (78.7%)	3.87	4
I know where to find helpful health resources on the Internet	17 (5.7%)	16 (5.3%)	267 (89.0%)	4.04	4
I know how to find helpful health resources on the Internet	8 (2.7%)	10 (3.3%)	282 (94.0%)	4.19	4
I know how to use the Internet to answer my questions about health	6 (2.0%)	17 (5.7%)	277 (92.3%)	4.20	4
I know how to use the health information I find on the Internet to help me	4 (1.3%)	35 (11.7%)	261 (87.0%)	4.12	4
I have the skills I need to evaluate the health resources I find on the Internet	21 (7.0%)	40 (13.3%)	239 (79.7%)	3.98	4
I can tell high quality health resources from low quality health resources on the Internet	24 (8.0%)	59 (19.7%)	217 (72.3%)	3.85	4
I feel confident in using information from the Internet to make health decisions	30 (10.0%)	74 (24.7%)	196 (65.3%)	3.76	4
			Total	4.00	4

Table 3

Trust and Difficulty in Finding Health/Genetic Information.

	Baseline (n=277)			1-Week Follow-up* (n=56)			3-Month Follow-up*		
	1/2	3	4/5	1/2	3	4/5	1/2	3	4/5
It took a lot of effort to get the information you needed.	82.7% (229)	3.6% (10)	13.7% (38)	62.5% (35)	12.5% (7)	25% (14)	80.8% (63)	15.4% (12)	3.8% (3)
You felt frustrated during your search for the information.	84.5% (234)	5.1% (14)	10.5% (29)	71.4% (40)	14.3% (8)	14.3% (8)	83.3% (63)	12.8% (10)	3.8% (3)
You were concerned about the quality of the information.	51.3% (142)	15.2% (42)	33.6% (93)	48.2% (27)	21.4% (12)	30.4% (17)	58.4% (45)	24.7% (19)	16.9% (13)
The information you found was hard to understand.	92.1% (255)	4.7% (13)	3.2% (9)	64.3% (46)	21.4% (12)	14.3% (8)	83.3% (65)	12.8% (10)	3.8% (3)

1=strongly disagree; 2= disagree; 3= undecided; 4= agree; 5= strongly agree

* of participants who indicated searching for health information related to T2DM genomic risk result