Published in final edited form as:

J Genet Couns. 2014 June ; 23(3): 401–408. doi:10.1007/s10897-013-9674-3.

Public Trust in Genomic Risk Assessment for Type 2 Diabetes Mellitus

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Abstract

Patient trust in personal medical information is critical to increasing adherence to physician recommendations and medications. One of the anticipated benefits of learning of one's genomic risk for common diseases is the increased adoption of screening, preventive care and lifestyle changes. However, the equivocal results thus far reported of the positive impact of knowledge of genomic risk on behavior change may be due to lack of patients' trust in the results. As part of a clinical study to compare two methods of communication of genomic risk results for Type 2 diabetes mellitus (T2DM), we assessed patients' trust and preferred methods of delivery of genomic risk information. A total of 300 participants recruited from the general public in Durham, NC were randomized to receive their genomic risk for T2DM in-person from a genetic counselor or online through the testing company's web-site. Participants completed a baseline survey and three follow-up surveys after receiving results. Overall, participants reported high levels of trust in the test results. Participants who received their results in-person from the genetic counselor were significantly more likely to trust their results than those who reviewed their results on-line ($p=0.005$). There was not a statistically significant difference in levels of trust among participants with increased genetic risk, as compared to other those with decreased or same as population risk ($p = 0.1154$). In the event they undergo genomic risk testing again, 55% of participants overall indicated they would prefer to receive their results online compared to 28% that would prefer to receive future results in-person. Of those participants preferring to receive results online, 77% indicated they would prefer to have the option to speak to someone if they had questions with the online results (compared to accessing results online without the option of professional consultation). This is the first study to assess satisfaction with genomic risk testing by the method of delivery of the test result. The higher rate of trust in results delivered in-person suggests that online access reports may not result in serious consideration of results and lack of adoption of recommended preventive recommendations.

Keywords

genetic counseling; genomic testing; type 2 diabetes; patient trust; personalized medicine

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A hallmark of the era of personalized medicine is the use of genomic information to predict disease susceptibility and inform therapeutic decision-making. Rapid technology development and accumulation of knowledge of genomic associations have led to the development of many new tests, available through a physician's office or online direct-to-consumer (DTC) companies. Patients receiving clinical genetic testing through their health provider would typically have the opportunity to discuss the risks, benefits and limitations of testing before ordering to inform decision-making and then review the results and options to reduce increased disease risks. In comparison, while patients who choose to order a genomic test through a DTC company may appreciate the flexibility of ordering the test and reviewing the results at their convenience and maintain their privacy, many companies do not provide access to a healthcare provider (Geransar and Einsiedel 2008; Gollust et al. 2003). As a result, consumers of DTC tests may misunderstand the benefits, risks, and limitations of testing as well as the actual results, experience undue anxiety, or undergo unnecessary follow-up testing, (Hogarth et al. 2008). However, no substantial adverse consequences have been reported (Bloss et al. 2011).

Consumers' level of trust and confidence with respect to the validity or accuracy of a test result may differ between those who access testing and results online compared to through a physician's office. Trust is an important component of healthcare impacted by many factors. Trust has been linked to patient satisfaction, improved communication and joint decision-making, and decreased patient anxiety (Hall et al. 2002; Trachtenberg et al. 2005). In genetics, the level of trust may affect the utilization of genetic testing and participation in genetics research (Brunk 2006; Cunningham-Burley 2006). Provider-patient interaction is a key part of establishing trust in both the provider and information being delivered, a component missing in the DTC testing model. Communication of test results via an online portal leaves consumers on their own to interpret the result and decide about the significance and validity of the results, potentially further heightening doubts in the validity of the test result and causing anxiety and confusion.

Trust can critically affect health-related behaviors. Leventhal's Common Sense Model (CSM) of self-regulation captures the importance of trust as it may impact how risk information is perceived and how this perception is translated into a behavioral response, based on a patient's beliefs about duration of illness, seriousness or effects of illness, treatment success (control, cure, or in this case, prevention), and causes of illness (Marteau and Weinman 2006; Rees et al. 2004). The level of trust and confidence in the DTC test result may impact how likely one is willing to engage in preventive behaviors or seek additional health information. Trust in the information source, including online sources, has been associated with higher likelihood to make health changes (Bleich et al. 2007; Huh et al. 2005; Huston et al. 2009) and increased self-efficacy to make changes (Hillen et al. 2011; Ye 2010). Although patient trust in web-based health information has been reported to be comparable to that received from a health professional (Hesse et al. 2005; Vega et al. 2011; Zulman et al. 2011), it is unclear how consumers regard DTC genomic testing, a process that occurs online entirely. Given the varying quality of health information online (Bernhardt et al. 2002; Eysenbach and Kohler 2002), motivating information-seekers to "comparison shop" for health information, the perceived credibility of the information source ("source credibility") may impact trust (Freeman and Spyridakis 2004; Wagner et al. 2012).

To our knowledge, consumer trust in DTC testing and online delivery of test results has not been extensively studied, but given its potential ramifications for health behaviors, it is important to consider this factor if online delivery of test results becomes more widely used. Even for tests ordered through a physician's office, patients likely can access their test results through a patient portal to their electronic health record, potentially resulting in short-term anxiety and confusion until they can review the result with their provider. As part of a larger trial comparing delivery methods for genomic risk comprehension for Type 2 diabetes mellitus (T2DM), we examined participants' level of trust, satisfaction and preferred delivery methods for future testing.

Methods

Participants and Procedures

As previously reported (Haga et al. 2013), this study was approved by Duke University Medical Center Institutional Review Board and all participants were consented prior to participation. Participants were informed of the limitations of testing, specifically regarding the limited knowledge of the genetic causes of T2DM which is understudied in some populations and the environmental factors on disease risk. They were also informed that testing would be performed by deCODE Genetics and not Duke University. Participants completed a baseline survey at initial intake and provided a DNA sample for T2DM susceptibility testing. Educational materials were provided to all participants with their enrollment folder, including materials developed by federal agencies and professional disease organizations (e.g., American Diabetes Association) to increase general knowledge about genetics and T2DM and ways to reduce disease risk, prepare individuals for the type of information they will receive in the study, and reduce disparities in knowledge due to variability in information-seeking skills. Materials were written at a 5th-7th grade reading level.

Participants were randomized to receive results either 1) in-person with a genetic counselor, or 2) online via the deCODEme website. Both groups were provided access to their test report which included scientific details about the SNPs tested, individual relative genetic risk, lifetime risk estimate based on relative genetic risk, gender and race, and information about additional risk factors such as diet and exercise associated with T2DM risk. The genetic counselor discussed each section of the report with the participant; those randomized to receive the results online could select sections of the test report to review on the website.

Instrumentation

Participants were asked to complete four surveys: baseline (pre-testing), and 1-week, 3-months, and 6-months post-testing. In the 1-week post-testing survey, we assessed participant understanding of test result, risk perception, psychosocial impact, trust and satisfaction, and delivery preferences for future genomic risk assessments. Understanding of the result, risk perception, psychosocial impact, and trust and satisfaction were also assessed 3 months following testing; assessment of understanding of results, trust and satisfaction was repeated at 6 months post-testing. Level of trust was measured ("Did you trust your test result?") with a 5-point scale (Completely trust, Somewhat trust, Uncertain / Don't know,

Somewhat do not trust, Do not at all trust); no definition of trust was provided. Satisfaction was assessed by ascertaining participants' likelihood to have testing again ("Now that you know the result, would you have taken test in the first place?") also using a 5-point Likert scale ["Very likely" (1) to "Not at all likely" (5)]. Participants were asked to select their preferred delivery method for future testing of six options presented (in-person by their health provider or a genetic specialist; mailed with or without the option to consult a health provider; and online with or without the option to consult a health provider). Importance of other factors in understanding was measured using a 4-point scale (Very important, Somewhat important, Not very important, Not at all important). We describe the results regarding trust and satisfaction and delivery preferences for future genomic risk assessments here; results on other findings will be published separately.

Data Analysis

Contrasts in dichotomized responses were drawn using Pearson chi-squared tests with continuity correction. 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

Participants

As described elsewhere, 300 individuals were recruited from the general public in Durham, NC (Haga et al. 2013). Eligible participants were at least 18 years of age, English-speaking, had internet access, and no prior history of T2DM or having had a genetic test to predict T2DM risk. Participants were primarily female (70%), between 18–29 years of age (44%), had a Bachelor's degree or higher (65%), and self-reported as White (60%). Seventy percent of participants also reported a family history of T2DM. A total of 257 participants (86%) reviewed their test result and completed the 1-week follow-up survey.

Trust in Genomic Risk Assessment

When asked if they trusted their test result 1-week after receiving it, the majority of participants indicated that they completely (37%) or somewhat (51%) trusted the test result (Table I). The level of trust in participants with increased genomic risk (92%) was not significantly different than in other participants (88%) ($p = 0.79$). Among participants with a family history, the level of trust still did not vary significantly with the level genetic risk; 90% of those with increased risk trusted the results and 84% of those with decreased or same as general population risk trusted the result ($p = 0.30$). In addition, there was no relationship observed between level of trust and genetic knowledge ($p = 0.97$), age ($p=0.93$), education level ($p=0.38$), family history ($p=0.45$), or history of online information seeking ($p=0.53$). A weak association was observed between race and level of trust with non-Caucasian participants less likely to trust the test results than Caucasian participants ($p=0.06$).

When trust was examined between study arms for some of the above variables, some significant differences were noted. In particular, participants receiving their results in-person were more likely to indicate trust (complete or somewhat) in the test result (94%) than those that accessed their results online (83%) ($p=0.013$). Likewise, those with a family history that received their results from the genetic counselor were more likely to trust the results than those that accessed the results online ($p=0.03$).

Moderate agreement was observed between levels of trust indicated at 1-week and at 3 months ($\kappa = 0.40$) and between 3 and 6-months ($\kappa = 0.54$), however disagreement did not change in the positive or negative direction ($p = 0.69$ and $p=0.39$, for 3- and 6-months, respectively). At 3-months and 6-months there was no longer a statistically significant difference between participants receiving results in-person versus online (94% versus 89%, $p = 0.24$ at 3-months, and 94% versus 91%, $p = 0.70$ at 6-months).

Satisfaction with Testing

One week after receiving their results, participants were asked if they would have had the test now knowing the result: 71% indicated that they would have definitely taken the test and 19% would probably have taken the test. No significant difference in participant satisfaction was observed by study arm (91% of participants who received their results in-person vs. 89% of participants who received their results on-line would have definitely/probably have taken the test) (Table I). The proportion who indicated that they completely or somewhat trusted the test result were more likely to indicate that they definitely would have taken the test (73%) versus those who didn't trust the result (55%) ($p = 0.061$). There was no significant association between participant satisfaction and perceived risk (low/intermediate vs. high). No increases or decreases were seen in the proportion of participants who would definitely take the test from 1- week to 3 months ($p = 0.26$) or from 3 to 6 months post-testing ($p = 0.45$).

To determine participants' perceived value of learning of their genomic risk for T2DM, we asked participants to indicate the level of importance of the information for five purported benefits: 1) learning about the specific genetic variation; 2) learning about the percentage of people who have the same DNA result as you; 3) learning about your genomic risk score for T2DM; 4) learning about the scientific research behind the test; and 5) learning about healthy behaviors to reduce risk of T2DM (Table II). Of the five perceived benefits, the largest proportion of participants indicated that learning about healthy behaviors to reduce risk of T2DM was very important (74%). Sixty-six percent of participants believed that learning of their genetic risk score for T2DM was very important. Fewer than half of the participants considered the remaining three potential benefits less important: learning about the scientific research behind the test (41%), learning about the specific genetic variants (39%), and learning about the percentage of people who have the same genetic risk (38%).

Delivery Preference for Future Testing (Table I)

One week following receipt of the T2DM results, participants were asked their preference for receiving results for future testing: in-person from their doctor or a genetic specialist or by mail or online (with or without the option to speak to a professional). Overall, 55% of

participants indicated they would prefer to receive their results online for future genomic risk testing with or without the option to speak to someone if they had questions about their results (77% of those that preferred to receive their results online wanted the option to consult a health professional) (Table III). In contrast, 23% indicated they would prefer to receive future results in-person from a genetics professional and 5% preferred to receive the results in-person from their own physician. Participants in the study arm that received their test result online were significantly more likely to prefer receiving results online with or without the option to speak with someone (66% versus 44; $p=0.0007$).

Discussion

Major Findings and Practice Implications

New technologies unfamiliar to patients may be looked upon askance due to lack of trust (Pivetti et al. 2012). In our study, we find that the majority of participants reported a high level of trust in the genomic test result and satisfaction with testing for T2DM. However, those who received their test result in-person from a genetic counselor were more likely to express greater trust than those who received their results online. To our knowledge, this is the first study to assess trust and satisfaction of genomic risk testing by the method of delivery of the test result and demonstrates the benefit of the involvement of a genetic counselor in the delivery of DTC testing

The active exchange of medical information between patient and provider can improve patient satisfaction (Hou and Shim 2010; Keating et al. 2002). Patients that have developed a relationship with a health provider and perceive them to be competent are more likely to be more trusting (Hillen et al. 2011). Thus, given the reported positive effect of provider engagement on trust, it is not surprising that we found a higher level of trust among participants receiving their results in-person with the genetic counselor than those who accessed the results online. Although the communication of the result was by a genetic counselor not associated with participants' regular healthcare provider, trust of the result may have been heightened due to their recognition that she is an expert and also familiar to them, having met with them in-person during enrollment and maintaining continuous contact throughout the study (approximately 9- months).

Several characteristics have been associated with patient trust, notably education level (Halbert et al. 2009; Kraetschmer et al. 2004; O'Malley et al. 2004) and race (Berrios-Rivera et al. 2006; Keating et al. 2004), with White patients reporting greater trust in physicians (Armstrong et al. 2007; Doescher et al. 2000; Keating et al. 2004; Rawaf and Kressin 2007) and the healthcare system (Smedley et al. 2003) than non-White patients. In our study, we did not observe any association between trust and genetic knowledge, or trust and educational level, perhaps due to the relatively high level of genetic knowledge of participants (Haga et al. 2013). Greater familiarity with a new technology such as genomic testing may lead to greater support and confidence, but can also result in increased skepticism and caution (Jallinoja and Aro 2000; Rose et al. 2005; Sturgis et al. 2005). We did observe a weak association between race and trust in the test result. Concerns about racial discrimination, genetic discrimination (Peters et al. 2004), and misuses of genetic testing (Bates et al. 2005; Zimmerman et al. 2006) are prevalent in minority populations,

potentially impacting the use of clinical genetic services (Armstrong et al. 2003) and participation in genetics research (Bussey-Jones et al. 2010; Corbie-Smith et al. 1999). Distrust from minority populations likely stems from a combination of past mistreatment of minorities by the medical community (Gamble 1997) as well as continuing feelings of underlying racism (Gamble 1997; Jacobs et al. 2006) and limited access to healthcare services (Flores and Tomany-Korman 2008; Joshi et al. 2012; Mahmoudi and Jensen 2012).

Despite the lower level of trust reported by participants in the online arm, these participants would still prefer to review results online for future testing, but with the option to speak with a healthcare professional if needed. However, it will be important that the provider be knowledgeable about genetics or refer to a genetics professional in order to provide appropriate interpretation and guidance, as lack of genetics and genomics knowledge in non-genetics professionals has been a noted limitation with potentially harmful outcomes (Wood et al. 2008; Brierley et al. 2010; Vande Wydeven et al. 2012; Benseid et al. 2013).

Electronic medical records are changing the relationship between provider and patients and increasing transparency, information exchange, patient satisfaction and management of chronic diseases and increased efficiency of office visits (Urowitz et al. 2012; Wade-Vuturo et al. 2012). Efforts to “personalize” patient portals may further increase patient understanding, utilization and satisfaction (Koonce et al. 2007). For example, regular use of a diabetes-specific portal was more likely in patients who accessed information that was personalized and interactive as compared to those that viewed general information about diabetes care (Koonce et al. 2007). For online genetic tests, development of personalized reports based on information provided by the consumer could encourage careful review and use of their test results. For patients that request to consult with a provider associated about their test results, online group informational sessions with general information may be offered (Axilbund et al. 2005) as well as individual consultations via phone, a web portal or chat room (Coelho et al. 2005; Hilgart et al. 2012; Meropol et al. 2011). The use of online-based educational interventions in combination with traditional in-person counseling has been reported to be effective (Green et al. 2005; Green et al. 2004). Similarly, medical specialties are exploring the efficacy of online clinical interventions (Cockayne et al. 2011; Klein et al. 2013; Levine et al. 2011).

Patient trust has been reported to be predictive of behaviors such as adherence to preventative services (Jones et al. 2012) and treatment (Safran et al. 1998; Trachtenberg et al. 2005). DTC testing has not been shown to have much of an impact, negative or positive, on behavior or overall understanding of disease risk (Bloss et al. 2011; Bloss et al. 2013; James et al. 2011; McBride et al. 2010). Our preliminary data analysis of diet intake (fat, fiber, and fruits/vegetables based on participant recall) and physical activity from our study also suggests no or minimal impact of knowledge of T2DM risk on health behaviors (Haga et al., unpublished). Since our results suggest that trust in the test result is relatively high, trust may be less of a factor impacting behavior than hypothesized for genetic testing. Other potential factors or combination of factors such as risk comprehension, perceived risk, perceived self-efficacy, and knowledge about how to reduce disease risk through lifestyle or other changes may have greater impact on behavior change based on genetic risk information. Particularly, our study population indicated that learning about healthy behaviors to reduce T2DM risk was an important part of their understanding of the test

result. Relying on patients/consumers to gather, understand, and implement an effective lifestyle change on their own is not realistic, and thus, health professionals who understand health interventions as well as genetics and genomics will be needed to help realize the benefits of DTC testing.

In addition to increasing trust and utility in test results, there are other benefits to provider involvement with DTC testing and online risk communication. Some providers, particularly geneticists and genetic counselors have questioned the science and clinical usefulness of DTC testing (Hock et al. 2011; Howard and Borry 2013). Many of these concerns are warranted, but few are fully addressed on the DTC company websites. Therefore, genetic counselors have an important role in helping patients understand the basis and limitation of DTC test results. Furthermore, patients interested in genomic risk may be more willing to engage in discussions regarding preventive health, and thus, providers have an opportunity to discuss other risks factors with greater predictive value and preventive screening guidelines or healthy lifestyles to reduce disease risks.

Study Limitations and Research Recommendations

Some study limitations should be noted. The T2DM test used in this study is not a test routinely ordered by medical professionals and differs from other DTC tests on the market as it only provides risk information for one condition instead of analyzing many genetic variants associated with a number of health conditions. Therefore, these results may not be generalizable, although most DTC tests for disease risk include testing of the genes on the panel used. Despite our efforts to recruit a diverse study population, participants were primarily younger, White and highly educated from the Durham region, potentially limiting the generalizability of our findings. Participants may be positively biased toward genetic testing given their interest in enrolling in the study and high risk family history and thus, may not be representative of the general public's attitudes. Responses to survey questions about trust may have been subject to participant biases and past health care experiences (not ascertained) as well as interpretation of the meaning of "trust" as a specific definition of trust was not provided. Given these limitations, additional research is needed to understand the impact of online risk communication of genomic results for a more general population.

In summary, the increasing use of online access of health information, including genomic risk assessments, warrant continued development and refinement to promote trust, understanding and utilization. Access to a trained health provider is important to promote comprehension and knowledge of lifestyle changes to reduce risks. As it is anticipated that most patients/consumers will not have access to a genetics health professional, it is even more important for genetic counselors to aid in developing the tools and resources needed to establish patient understanding and trust and encourage adoption of health behaviors.

Acknowledgments

This work was funded by the U.S. National Institutes of Health (1R21HL096573-01A1) and was partially presented as a poster presentation at the 2012 National Society of Genetic Counselors Annual Education Conference. We are grateful for the statistical support provided by Dr. Sunil Suchindran. Disclosures: R.M provides contracting services for the laboratory testing company GeneDx. W.B. declares no conflict of interest. S.B.H. serves as a consultant to the Inova Translational Medicine Institute of Inova Health Care Services (non-profit).

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Table I

Impact of study delivery method on trust, preference for future delivery method, and satisfaction/regret with testing at 1-week post-testing (significance value is for in-person vs online study arms).

	Overall	In-person	Online	p-value
Completely/ Somewhat Trusted Test Results (All Participants)	88%	94%	83%	0.013
Completely/ Somewhat Trusted Test Results (Participants at Increased Genomic Risk)	92%	100%	85%	0.48
Completely/ Somewhat Trusted Test Results (Participants Reporting Positive Family History)	87%	93%	80%	0.03
Satisfaction/Regret (Very/probably likely to have had testing after receipt of results)	90%	91%	89%	0.66

Table II

Importance of factors that affect perceived understanding and use of genomic test results

Factors affecting understanding and use of genomic test result	Very Important	Somewhat Important	Not very important	Not at all important
Learning about healthy behaviors that can reduce diabetes risk	74.5%	24.3%	1.2%	0%
Learning about your genomic risk score for diabetes	66.3%	29.8%	3.53%	0.4%
Learning about the percentage of people who have the same result as you	37.6%	46.7%	35.3%	0.4%
Learning about the specific genetic variation (genotype)	39.2%	43.9%	14.9%	3.5%
Learning about the scientific research behind the test	41.2%	41.6%	15.7%	1.6%

Table III

Delivery Preference for Future Test Results (significance value is for in-person vs. online study arms).

	Overall	In-person	Online	p-value
Mailed letter with or without the option to speak with someone	16%	21%	12%	0.07
Online Delivery with or without the option to speak with someone	55%	44%	66%	0.0007
In-person from doctor/In-person from a genetics professional	28%	35%	22%	0.03