

PRIVACY IN A GENETIC AGE

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ABSTRACT

Privacy has become one of the most enduring issues people have to deal with, and this is increasingly so as technology advances in the field of genetics and medicine. Are people comfortable sharing access to their medical and genetic information, and if so, who with? Genetic privacy is particularly important because testing in this area is largely predictive, and the presence of a gene does not guarantee the presence of cancer or another disorder. In 2008, the federal Genetic Information Nondiscrimination Act was passed to keep employers and health insurers from discriminating based on genetic information, but is that enough? This study analyzed responses to over 500 questionnaires to determine whether respondents trusted different people (doctors, researchers, etc.) and organizations (health insurers, law enforcement, etc.) with information as sensitive as medical and genetic records. Overwhelmingly, we found that medical and genetic confidentiality is very important, and that people are far more trusting of doctors and researchers than they are of those outside the medical field. People are generally distrustful of national online medical databases, especially if information is being entered without the patients' knowledge or consent. Finally, we discovered a very significant difference between how much access respondents believe that individuals or organizations have to their medical records and how much access respondents feel these individuals or organizations should have. Our findings indicate that people value medical and genetic confidentiality and would like to limit the amount of access that non-medical groups have to their records.

INTRODUCTION

The United States currently spends around 15% of its gross domestic product on healthcare, and that number is rising. Since insurance companies make profits by predicting health risks and setting premiums to compensate for them, genetic screening and privacy rights are becoming some of the biggest ethical issues concerning policymakers today. How much medical or genetic information do insurance companies have the right to, or for that matter, how much access does anyone have the right to? Under what conditions should genetic screening be undertaken?

When the Human Genome Project began in 1990, the project included several goals, including the sequencing of the 3 billion base pairs, the identification of all the genes contained within the genome, improving the sequencing technology necessary, and a continued study of the social, legal, and ethical implications of this new information (Knoppers, 2006). The aim of this paper is also to study perceptions people have of the ethical implications of genetic screening in the context of genetic privacy in the United States. This will include an extensive literature review of state, federal, and international genetic legislation, the different circumstances under which one takes a blood test, and a discussion of the concept of privacy, and how it has evolved in America. It will also include the results and findings from over 500 responses to a 75-question online survey.

The insurance industry sells insurance for premiums, which they determines based on a variety of factors including age, gender, health, lifestyle, and many others. They then collect these premiums from everyone, hoping to have to pay out big claims on only a small percentage of those they collect from and making a profit in the process. Genetic screening could be very helpful for insurance companies in this scenario, because it could identify future health risks for an individual. This would provide the insurance company with a basis for refusing to sell to an individual (Hall, 2000). Employers also have a stake in the genetic make-up of their employees. By screening out anyone who might potentially develop breast, colon, or some other type of cancer, the employer can protect himself/herself from additional health-related costs.

Unfortunately for the individual in this scenario, genetic testing tells more than just the genes a person has. By its very nature, genetic screening reveals genes found in a family, which could cause other people to be denied health insurance or subjected to other forms of discrimination, if this information were readily available to everyone. This violates the privacy of the individuals' family members, who did not undergo genetic screening themselves. Genetic screening is also limited in that it cannot predict whether a gene will become active or if/when a person will get sick (Wolf, 2006).

Many states have recently enacted laws that restrict health insurance companies from denying coverage to an individual based on genetic screening because health insurance is important as a community resource and the risks should be shared by all. These regulations do not, however, cover death insurance or disability insurance, nor are they present in every state (Rothenberg, 1997). The recent Genetic Information Non-discrimination Act of 2008 unifies state legislation and makes it illegal for health insurers and employers to discriminate based on genetic testing results.

Genetic discrimination has already occurred in several instances in the U.S. based on a potential future determined by a few drops of blood. The ethics of privacy are quickly coming to the forefront of public policy and research on this subject could not be timelier (Annas, 1995).

METHODS

(Modeled on the article *Using the Internet for Online Survey Research: A Case Study*)

Survey Instrument: A survey questionnaire to collect data that would help to obtain a better understanding of the levels of trust different individuals have with regard to sharing their genetic information. The data included general demographic information, comfort levels when sharing information with different people or groups, opinions on online databases, feelings on how much access to medical records people do and should have, the Trust in People Scale (Survey Research Center, 1969) and the Health Locus of Control Scale (Wallston, Wallston, & DeVellis, 1978).

Survey Distribution: The survey was distributed entirely online. The link was posted on medical blogs and several organizations were contacted so that their members might participate. Responses were completely voluntary and participants were free to discontinue at any time.

Web Survey Application: A Web survey application was designed in SurveyMonkey for this research project by this author. It was used to generate surveys, and to collect survey data via the Internet.

Procedure: Using the web browser, a respondent can progress through the survey in the following way:

- 1) Load the survey main page. Once a respondent locates the survey website with a Web browser displays the survey main page, which explains the purpose of the survey, gives contact information for the researcher, and verifies the presence of informed consent.
- 2) After informed consent is verified, respondents complete the survey through an interactive process. Once the respondent completes the survey form, the browser navigates to a screen indicating that the survey has been completed and thanking participants for their time.

Survey Data Processing: Once all the survey data was gathered in an electronic form, it was downloaded into Microsoft Excel for further data analysis. Excel files were then transferred to the statistical software package SPSS for correlations and other tests of trends etc. (Zhang, 2000).

Alpha Level for all correlations is .05.

Reported reliability for borrowed questions:

Trust in People Scale: .48-.54

Multidimensional Health Locus of Control Scale: .61-.8

RESULTS:

After posting the questionnaire on several medical blogs, social networking websites and distributing it through organizations, 392 completed surveys were received in the designated three-week data-gathering phase. Several statistical tests were then run to analyze the information. Through these tests, it was established that respondents generally feel very strongly regarding the privacy of their medical and genetic information, and that people who are generally trusting will trust more people or organizations with this information. Respondents also tended to feel strongly that permission should be granted before medical or genetic records were used. This section contains the results for four hypotheses.

Hypothesis One: People will oppose their records going into the National Online Database without permission.

To determine how people feel about their records going into a national online database, a series of questions were asked. The first set of four questions asked how comfortable respondents were with certain types of information being stored in online databases, with possible responses of: very comfortable, somewhat comfortable, not too comfortable, not at all comfortable.

Table One

	Very Comfortable	Somewhat Comfortable	Not too Comfortable	Not at all Comfortable
Financial	3.2%	41.8%	36.7%	18.2%

Employment	16.2%	55.4%	20.5%	8.0%
Medical	6.7%	39.3%	32.0%	22.0%
Educational	26.7%	56.7%	12.1%	4.5%

In each case, the most frequent answer was that respondents were somewhat comfortable with their information being stored in online databases (See Table One). In the cases of financial and medical history, even though the largest percentage for a single category was for somewhat comfortable, more than 50 percent of people fall on the side of less comfortable. Whereas, over 70 percent of people are either somewhat or very comfortable with their employment and educational history being entered in to an online database.

Later in the survey, respondents were asked a second set of two questions. The first asked directly whether doctors and hospitals should have to obtain permission before they could release medical records to a national computerized database. On a one to six scale, with one being strongly agree and six being strongly disagree, respondents overwhelmingly said strongly agree, with over 80 percent of those surveyed choosing that option. The next question, with the same format of answers was: When you tell your doctor things about yourself in confidence, and the doctor records that information in your medical records, the doctor should be required to include that information in a national database without your permission. For this question, 69.9 percent of respondents strongly disagreed, with 14.8 percent disagreeing and 7 percent placing themselves somewhere between agreeing and disagreeing.

When Pearson correlation analysis was run between these two sets of questions, all eight tests came back significant at the .01 levels (See Table Two).

Table Two

Pearson Correlation Significance N	Doctors and hospitals should have to obtain your permission before they could release your medical records to a national computerized database.	When you tell your doctor things about yourself in confidence, and the doctor records that information in your medical records, the doctor should be required to include that information in a national database without your permission.
Online Database Comfort Level - Financial	-.181 .000 382	.200 .000 368
Online Database Comfort Level - Employment	-.164 .001 380	.128 .014 366
Online Database Comfort Level - Medical	-.193 .000 376	.235 .000 362
Online Database Comfort Level - Educational	-.167 .001 381	.191 .000 367

Hypothesis Two: People who are not generally trusting will not be trusting of others having access to their medical and genetic records.

In order to assess how generally trusting survey respondents were, the Trust in People scale (Survey Research Center, 1969) was included in the survey. The average answer to each of the three questions in the scale was obtained and added to the other two. This sum was then divided by three to form a new variable, GenTrust, to test against the idea of different groups of people (doctors, employers, etc.) gaining access to a respondent's medical and genetic records (Table Three).

Table Three

Pearson Correlation Significance N	GenTrust
I trust my health insurer to have access to my genetic test results	-.045 .394 367
I trust my employer to have access to my genetic test results	.038 .473 365
I trust my doctor to have access to my genetic test results	.131 .012 365
I trust researchers studying genetics to have access to my genetic test results	.219 .000 365
I trust my spouse to have access to my genetic test results	.136 .010 364
I trust law enforcement to have access to my genetic test results	.087 .096 366

There is a strong positive correlation between people who are generally trusting and people who trust their doctors, genetic researchers, and their spouses with their results from genetic tests. This indicates that people who scored lower on the general trust scale were less likely to trust their genetic testing results to doctors, researchers, and spouses.

The GenTrust variable was then tested against a series of questions designed to ascertain whom respondents would trust with and give their medical information to, and for what purpose (Table Four).

Table Four

Pearson Correlation Significance N	GenTrust
Researchers at a university conducting a study about a medical	-.224

condition that had affected some of your family members	.000 368
Government researchers conducting a study about a medical condition that had affected some of your family members	-.204 .000 368
A drug company interested in providing people with information and offers about new drugs and other health care products	.013 .805 368
A new health insurance plan that is offering better benefits at a lower cost than other plans in your local area	-.053 .309 368
A local hospital interested in providing people with information about how they might benefit from its preventive health programs	-.024 .643 368
An employer who was considering you for a new job	.023 .661 368

People who trust generally would support researchers, whether from universities or the government, using their medical records to study a medical condition. The tests showed that people who were less generally trusting were less likely to trust researchers, whether they are university or governmental. Significant results were not found for drug companies, health insurance plans, local hospitals or employers using medical records.

Finally, respondents were asked a similar question regarding who they would trust to use their genetic testing results, and for what purpose. These answers were also tested against the Gen Trust variable (See Table Five).

Table Five

Pearson Correlation Significance N	GenTrust
Researchers, to find new ways to diagnose, prevent or treat disease	-.130 .013 368
Doctors, to identify a person's risk of having a bad reaction to a particular medicine.	-.123 .018 368
Doctors, to identify a person's risk of a disease where treatment or medication exist	.002 .965 368
Doctors, to identify a person's risk of having a child with a serious genetic disease	-.064 .218 368
Doctors, to identify a person's risk of a disease where no treatment or medication exist	-.044 .402 368
Employers, to make decisions about hiring and promotion	-.055 .290

	368
Health insurance companies, to determine whom to insure or how much to charge	.004 .936 368

People with higher scores on the general trust scale tended to be more trusting of researchers and doctors who were trying to find adverse drug side effects. It also indicated that people with lower scores were less trusting of the same groups.

Hypothesis Three: There will be a strong sense of objection when it comes to non-medical groups (government, employers, health/life insurance companies) gaining access to medical and genetic records.

To determine how people feel about the confidentiality of their records a series of questions were asked. This set of four questions asked how important the confidentiality of certain types of information was, with possible responses of: very important, somewhat important, not too important, and not at all important (Table Six).

Table Six

	Very Important	Somewhat Important	Not too Important	Not at all Important
Financial	71.4%	23.2%	4.7%	0.6%
Employment	27.6%	44.1%	23.1%	5.1%
Medical	65.9%	26.7%	6.6%	0.9%
Educational	11.1%	31.7%	35.8%	21.4%

Overwhelmingly, people felt that the confidentiality of their financial and medical history was very important. Respondents also seemed fairly unconcerned regarding the confidentiality of educational information.

Later in the survey, respondents were asked whether medical or governmental researchers should be allowed to study their genetic information (for example, to identify genes thought to be associated with various medical conditions) without first obtaining their permission (Table Seven).

Table Seven

	Medical Researchers	Governmental Researchers
Strongly Agree	2.9%	1.3%
	4.8%	3.5%
	5.6%	3.0%
	5.6%	4.0%
	12.7%	13.6%
Strongly Disagree	69.1%	74.5%

Though the vast majority of respondents strongly disagreed with medical or governmental researchers using their medical records without permission, over five percent more people disagreed with it when the government was doing it. In another question, respondents were asked whether they would be inclined to give their medical records to different organizations for specific reasons (Table Eight).

Table Eight

Researchers at a university conducting a study about a medical condition that had affected some of your family members	96.2%
Government researchers conducting a study about a medical condition that had affected some of your family members	72.1%
A drug company interested in providing people with information and offers about new drugs and other health care products	24.0%
A new health insurance plan that is offering better benefits at a lower cost than other plans in your local area	23.5%
A local hospital interested in providing people with information about how they might benefit from its preventive health programs	47.3%
An employer who was considering you for a new job	2.5%

Respondents clearly feel more comfortable sharing their medical records with medical groups, such as researchers. There is a significant difference between how comfortable people are with sharing their medical records with medical groups and non-medical groups, such as drug companies and employers. A similar question was asked regarding how inclined people would be to share their genetic records, and for what reasons (Table Nine).

Table Nine

Researchers, to find new ways to diagnose, prevent or treat disease	92.3%
Doctors, to identify a person's risk of having a bad reaction to a particular medicine.	94.6%
Doctors, to identify a person's risk of a disease where treatment or medication exist	93.6%
Doctors, to identify a person's risk of having a child with a serious genetic disease	87.2%
Doctors, to identify a person's risk of a disease where no treatment or medication exist	77.2%
Employers, to make decisions about hiring and promotion	1.3%
Health insurance companies, to determine whom to insure or how much to charge	4.3%

Again, people are very favorable to the idea of giving their genetic tests to researchers and doctors for a wide variety of reasons. Fewer than five percent would give their information to employers and health insurance companies. Finally, we asked whether respondents trusted different people and organizations with their genetic information, regardless of the purpose it was being used for (Table Ten).

Table Ten

	Strongly Agree					Strongly Disagree
My Health Insurer	4.5%	8.1%	15.4%	12.1%	17.2%	42.7%
My Employer	0.8%	2.8%	8.4%	9.4%	20.6%	58.1%
My Doctor	59.1%	24.1%	10.4%	2.8%	1.3%	2.3%
Researchers	25.8%	17.4%	26.9%	12.0%	6.9%	11.0%
My Spouse	49.5%	25.8%	13.5%	3.8%	2.8%	4.6%
Law Enforcement	5.3%	5.6%	16.2%	11.9%	15.9%	45.1%

Well over half of the respondents either disagreed or strongly disagreed with giving their health insurers access to their genetic information, and the same was true for employers. Almost 75 percent of people strongly agreed or agreed with giving researchers access to their information, and the same was true for spouses. Over 60 percent of people disagreed or strongly disagreed with giving their genetic information to law enforcement

Hypothesis Four: The impressions people hold of how much access different people or organizations have and how much they should have varies.

In order to discover whether respondents felt that the amount of access that a particular person or group had was the correct amount, a series of questions was asked in the following format:

How much access do you *now* have to your medical records?

- Access to everything
- Limited Access
- No Access
- Unsure

How much access *should* you have to your medical records?

- Access to everything
- Limited Access
- No Access
- Unsure

Paired sample T-Tests were then run on these results to determine whether there was a significant difference between the way things are and the way things should be, with lower means being more access (Table Eleven).

Table Eleven

	Mean	t	df	Significance
How much access do you have to your medical records?	1.57	13.477	247	.000
How much access should you have to	1.02			

your medical records?

How much access does your partner have to your medical records?	2.27	13.876	212	.000
How much access should your partner have to your medical records?	1.57			
How much access do close relatives have to your medical records?	2.11	3.618	291	.000
How much access should close relatives have to your medical records?	1.96			
How much access does your employer have to your medical records?	2.75	1.726	203	.086
How much access should your employer have to your medical records?	2.69			
How much access does your health insurer have to your medical records?	1.49	-7.498	157	.000
How much access should your health insurer have to your medical records?	1.83			
How much access does your most frequently used doctor have to your medical records?	1.21	3.460	281	.001
How much access should your most frequently used doctor have to your medical records?	1.13			
How much access do other doctors involved in your healthcare have to your medical records?	1.64	3.790	195	.000
How much access should other doctors involved in your healthcare have to your medical records?	1.53			
How much access do doctors not involved in your healthcare have to your medical records?	2.51	-3.042	128	.003
How much access should doctors not involved in your healthcare have to your medical records?	2.67			
How much access do governmental agencies have to your medical records?	2.35	-3.889	81	.000
How much access should governmental agencies have to your medical records?	2.63			
How much access do pharmacies have to your medical records?	2.22	1.178	144	.241
How much access should pharmacies have to your medical records?	2.18			
How much access do drug companies have to your medical records?	2.78	-1.682	95	.096
How much access should drug companies have to your medical records?	2.83			

In eight out of the eleven cases, the amount of access people think that individuals or organizations have and how much they should have varies significantly. People feel reasonably comfortable with the amount of access that employers, pharmacies, and drug companies have to their medical records, and would maintain that. People would take access away from health insurers, doctors not involved in their healthcare, governmental agencies, and drug companies (though it is not statistically significant for drug companies). Respondents would increase their own access and the access held by their spouse, close relatives, their employer (though not significantly), their doctor, other doctors involved in their healthcare, and pharmacies (though not significantly).

DISCUSSION

Through analyzing the results of the online survey we were able to determine many factors that affect people's view of genetic privacy. There were several significant findings, including the fact that people are generally distrustful of having their records kept in online databases (especially their financial and medical records), and are particularly distrustful if the records are kept in computer-based databases without permission. We also found that people who are not generally trusting will be less likely to trust a variety of other people and organizations with access to their medical and genetic information. This was primarily shown with distrustful people not trusting doctors, researchers, or their spouses.

Additionally, we discovered that there is a strong sense of objection when it comes to non-medical groups (health insurance companies, law enforcement, etc.) gaining access to medical and genetic records. A large percentage of people found confidentiality important, but would trust researchers and doctors to have that information for a variety of reasons. They did not trust health insurance companies, employers, or law enforcement agencies with this information. Finally, we learned through a series of questions about how things are and how things should be, that in most cases, there is a significant difference between the amount of access people think different people or groups now have and how much they should have.

These findings all play into the idea of genetic privacy. Genetic information is different than any other kind of personal information because of its predictive nature, and the issue of additional protection for this material has already inspired national legislation. This research supports the idea that people are very concerned with the confidentiality of this information and that they are largely not comfortable sharing it beyond those in the medical sphere.

To uncover how people felt about their information being stored in online databases, we asked a number of questions within the survey. In the first set of questions, respondents replied that they would be least comfortable with their financial and medical information being stored in computer-based systems. This indicates that these two types of information are considered the most sensitive, and the ones that people most need to protect. Respondents overwhelmingly stated that medical records should not automatically go into databases without permission, and that information given to a doctor in confidence should not go into a database without permission. This suggests that people want to maintain a high degree of control over their medical records (over half of respondents felt that their medical records were information that they owned or controlled) and not have anything done regarding them without permission.

Over 60 percent of survey respondents claimed to be somewhat worried or very worried about the privacy of their medical records. When correlation tests were run, we determined that the people who were very concerned with their financial, employment, medical, and educational information going into online databases were also concerned about their medical records being entered into a database without permission, and information that they give their doctors in confidence going into online databases without permission. This supports the idea that people want to maintain their confidentiality to the largest extent possible, and also that they want to have a high degree of control over this information. This could be because people feel that online databases are harder to secure when it comes to illegal data gatherers, or because as a national database more people will have access to the information than would if the files were paper and stored in a doctors' office. Also, because this information is so sensitive, people may feel like they have to control it so that it will not come back and be damaging to them. They may perceive that if more people have access to their medical history or genetic testing results, it will affect the premiums that they pay for health, life, or disability insurance. The recently passed Genetic Information Nondiscrimination Act is not yet widely known (almost 80% of survey respondents were not familiar with it), and only prohibits health insurers from using genetic testing results in the underwriting process.

Respondents in this survey, as mentioned earlier, felt very strongly about allowing non-medical groups to gain access to their medical and genetic records. There are several possible explanations for this. One is that respondents may feel that people like doctors are generally on a need-to-know basis in order to enhance the health of the patient, and would not misuse the information. For employers and health insurers to have access to this information greatly increases the chances that harmful information in a persons medical history or genetic code would put them at a disadvantage outside of the realm of health. Another reason that doctors and researchers may be trusted more than other groups is because predominantly they have an air of confidentiality built in to their missions. Genetic information can be very harmful for a person and their family, so it is relevant that employers, pharmacies, drug companies, law enforcement, and insurance companies tend to not be as associated with this idea of confidentiality.

This is important because it shows that the Genetic Information Nondiscrimination Act of 2008 is on the right track by limiting the access that employers and health insurance companies have to genetic information. The act also adds additional protection for people who wish to participate in genetic studies, which is very positive, as our study found that people would be willing to donate their information to further genetic research. The act does nothing to tamper with the existing doctor-patient relationship, which is already strong, and actually encourages people to get tested so that they might get treatment without fear of rising health insurance premiums.

Part of the questionnaire analysis centered on determining whether people were generally trusting or generally not trusting. Once we were able to establish that, we were able to see whether the trusting people felt more comfortable sharing their medical and genetic information, or if this was the exception to the rule. Significant positive results occurred where trusting respondents were asked if they trusted their doctor, their spouse, or researchers with genetic information. Trusting people trust those in the medical field. The correlation was negative when asked about health insurers having that information, and positive when asked about law enforcement and employers, but not significantly so. This is

consistent with findings discussed earlier, that people are generally trusting of those in the medical field.

Similar questions regarding who and for what purpose someone would allow others to have access to medical records revealed that university and governmental researchers would be trusted by generally trusting people, but that drug companies, health insurance providers, and employers would not be. This could be because generally trusting people have a desire to do good things, and to give information to those whom they perceive to need the information. If trusting people were to follow those assumptions, they might be more comfortable relaxing the confidentiality of their records.

Finally, we discovered that there is a very significant difference between how much access a patient believes that different groups or organizations now have to their medical records, and how much access they should have. Respondents tended to believe that they and their most frequently used doctor should have access to everything, but that they did not now have that access. A noteworthy portion of the population was unsure as to how much access different groups had to their information (up to 79.2 percent in the case of how much access governmental agencies have to their medical records). Eight of the eleven paired T-Tests that were run revealed that there is a very significant (at the .01 level) difference between the way things are and the way things should be. In five of those cases, respondents felt that the individuals or groups should have more access than they do, and in three of those cases, less access was necessary than the status quo currently provides.

There are a number of possible explanations for these findings. One possibility is that there are so many questions surrounding the concept of medical confidentiality that no one really knows how things are, but they do know how they would like them to be. This is supported by the high percentage of unsure respondents when it came to access for drug companies, pharmacies, governmental agencies, doctors not involved in a patients' healthcare, employers, and insurance companies. Another possible explanation is that people want to strengthen their control of their medical records and have more power over which organizations get what information, in some cases taking away any access that a person or organization has.

These findings support the conclusions from our other hypotheses, that people are generally more trusting of people in the medical field, and people who are perceived as needing-to-know. Our results indicated that access should be taken away from health insurers, governmental agencies, and drug companies, as well as from doctors who are not involved in a patients' healthcare. More access should be given to spouses, relatives, the most frequently used doctor, and other doctors involved in a patients' healthcare. Interestingly enough, respondents are comfortable with the amount of access that employers have, with a score of one being complete access and a three being no access, employer access only went from a 2.75 to a 2.69, which is not a significant change.

This could have implications for future legislation. The Genetic Information Nondiscrimination Act has already curtailed access to genetic records for health insurers and employers, and HIPAA has been strengthened since it was originally passed as well, but clearly people want more medical privacy, particularly when it comes to non-medical groups gaining access to medical and genetic records. Beyond legislation, there is very little information available regarding who has how much access, and we have found that people typically want more control over these things as opposed to less.

CONCLUSION

Genetic privacy is changing and expanding rapidly. Within the timeframe of this study, federal legislation has been passed to keep individuals from being discriminated against by employers and health insurers, based on their genetic information. The Genetic Information Non-discrimination Act of 2008 was a huge step forward in privacy protection, and it put in place a minimum standard of legal defense without limiting what individual states can do. But is this act enough?

By analyzing the results gathered from over 500 online questionnaires, we were able to draw several conclusions about which people and organizations individuals are comfortable sharing their medical and genetic information with. Within our survey we included a General Trust Scale (Survey Research Center, 1969) as a control for how trusting people generally are, and to see whether that influenced the amount of access that individuals would share. Many of the questions in the survey asked respondents to rate their level of comfort when it came to sharing their records with different groups, such as health insurers, employers, law enforcement, and the government, and individuals, such as their spouse, close relatives, and their doctors.

Our findings were conclusive. People surveyed were more comfortable sharing access to their medical and genetic records with people in the medical profession, like doctors and researchers, or people they are close to, like a spouse. Generally trusting people are more likely to share access than people who are not generally trusting. No one seems to be particularly comfortable with medical and genetic records going into a national online database, particularly without permission. Finally, in many cases people do not feel that other individuals or organizations have the appropriate level of access, and would either remove or grant additional access from them. Demographically, respondents were fairly evenly distributed in terms of income level and political orientation, though more females than males responded, and the education level of participants was fairly high.

These results indicate that putting more protection in place for genetic privacy would not be unwelcome. The new legislation is a good step, but the safety from genetic discrimination does not extend beyond health insurance to life, disability, or long-term care insurance. Our findings also suggest that people tend to want a higher degree of control over their genetic testing results, which the 2008 Act does little to address.

Future research could look more deeply into the issue of control with regard to genetic and medical records. Are people with an external locus of control more likely to share access to their records? It might also be interesting to perform another study after GINA has been in effect for a few years, to see whether people are less concerned with their genetic privacy, and whether more people are undergoing genetic testing. One of the limitations of this study was that it was haphazard and a convenience sample, so a more randomly selected respondent pool might benefit future studies. Finally, future studies could explore further the idea of access, perhaps by telling respondents how much access different groups or organizations legally have and having the respondents add or subtract access based on the actual amounts as opposed to the perceived amounts.

Because science often moves far more quickly than the law, the concept of genetic privacy is rising in importance. It was not even a decade ago that the Human Genome Project was completed, and now scientists can isolate numerous genes, including those that can cause

inherited breast and colon cancer. Unfortunately, this potentially life-saving information does have the potential to hurt people through discrimination. Even though there are more safeguards against this form of discrimination now than there have been in the past, many people are still uncomfortable with the idea of sharing access to their medical and genetic information.

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