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Disclosure, Confidentiality, and Families:

Experiences and Attitudes of Those With Genetic Versus Nongenetic Medical Conditions

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Abstract

Despite policy attention to medical privacy and patient confidentiality, little empirical work exists documenting and comparing experiences of persons with genetic versus nongenetic medical conditions concerning persons' disclosure to others as well as their views about appropriate confidentiality to and within families. The goal of this cross-sectional interview study with nearly 600 participants was to document and compare the experiences, attitudes, and beliefs of persons with strictly genetic conditions to those of persons with or at risk for other serious medical conditions in terms of the degree to which they have disclosed to others that they have the condition and their views about how others ought to maintain the confidentiality of that information. While almost all participants reported that family members knew about their condition, results suggest participants want to control that disclosure themselves and do not want doctors to disclose information to family members without their knowledge. Similarly, participants do not think family members should be able to get information about them without

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their knowledge but feel overwhelmingly that it is a person's responsibility to disclose information about hereditary conditions to other family members. Ambivalence about confidentiality was evident: while most participants did not mind doctors sharing information with other doctors when it was for their benefit, the majority also felt that doctors should be punished for releasing information without their permission. The views and experiences reported here generally did not differ by whether participants had genetic versus nongenetic conditions, suggesting that the extensive policy focus on genetic information may be unwarranted.

Keywords

confidentiality; disclosure; family members; hereditary disease; cross-sectional survey

INTRODUCTION

Much attention has been paid to policy issues involving medical privacy and patient confidentiality in the United States, the result of which is an abundance of federal and state laws aimed at protecting patients. Because of concerns that these laws may provide inadequate protection, the Department of Health and Human Services, under powers decreed by the Health Insurance Portability and Accountability Act of 1996, released an overriding rule that preempts these laws only when the rule is stricter than the federal or state laws in question [Gostin, 2001]. However, state laws generally require that genetic information have special protections, in addition to those afforded general medical information [Annas, 2001]. Therefore, although some have argued that genetic information is not, in most ways, substantially different from other medical information [Beckwith and Alper, 1998; Gostin and Hodge, 1999], such information is still generally treated differently.

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Results of survey studies performed on those with genetic conditions or family histories indicated that people overwhelmingly believe that insurers and employers should not know about their condition or history and also that patients, not physicians, should be the ones responsible for informing at-risk family members [Lapham et al., 1996; Lehmann et al., 2000]. However, little empirical work exists documenting and comparing experiences, attitudes, and beliefs of persons with strictly genetic versus other medical conditions concerning individuals' own disclosure to others as well as their views about appropriate confidentiality to and within families.

The goal of this cross-sectional interview study was to document and compare the experiences, attitudes, and beliefs of persons with genetic conditions [cystic fibrosis (CF) or sickle cell disease (SCD)] to those with other serious medical conditions [diabetes, HIV, breast cancer (BC), or colon cancer (CC)] as well as those with a strong family history of

BC or CC, referred to here as “at risk.” These groups were compared in terms of the degree to which they have disclosed to others that they have the condition in question and their views about how others—especially family members versus providers, employers, insurers, etc.—should maintain the confidentiality of that information.

MATERIALS AND METHODS

Study Participants

Study participants were enrolled from March 1996 to February 2000. Initially, 100 respondents were sought from each of four disease groups: CF, SCD, diabetes, and HIV infection. Respondents were either adults (aged 18–64) affected by disease (CF, SCD, diabetes, and HIV) or parents of children affected by disease (CF, SCD, and diabetes). In October 1997, we added two disease groups: BC and CC, each composed of 100 individuals. In each of these groups, 50 individuals had a personal history and family history (at least one affected first-degree relative) of cancer, and 50 had only a family history of the cancer in question. Respondents were recruited from clinics or ongoing research studies of the Johns Hopkins Medical Institutions, disease registries of the Maryland Department of Health and Mental Hygiene, and advertisements in Baltimore newspapers.

A total of 602 individuals completed interviews. Three interviews were excluded because participants were over age 64, and two others provided too few responses to be informative, resulting in a final sample size of 597. Throughout this article, we use the term “affected adults” to mean adult respondents with the medical condition, “parents” to mean respondents with a child with the medical condition, and “at-risk adults” to mean respondents with a family but not personal history of cancer. The conditions referred to herein as genetic are defined as single-gene disorders with predictable patterns of inheritance (CF and SCD), and all other conditions (including at-risk) are considered to be nongenetic, defined here as multifactorially determined diseases that are not traditionally considered genetic but that most likely involve some combination of genetic (somatic or germ-line) and environmental components.

Interview

One structured interview was administered by a trained interviewer to each participant. Half the participants were interviewed in person and half were interviewed via telephone, based on the respondent’s preference. Written informed consent was obtained from those interviewed in person; oral consent was obtained for telephone interviews. Interviews lasted approximately 45 min, and participants were compensated $20 plus travel expenses. The survey included items related to knowledge, attitudes, and experiences with privacy, disclosure, confidentiality, discrimination, employment, insurance, and demographic information. Here, quantitative analyses of responses to those items related to confidentiality, disclosure, and the family are reported. The protocol was approved by the institutional review boards at Johns Hopkins Medical Institutions and the Maryland Department of Health and Mental Hygiene.

Analysis

Responses to survey questions were cross-tabulated with demographic variables, and the Pearson chi-square test for independence was performed on these contingency tables. Responses to each of the questions were examined by disease group (CF, SCD, diabetes, HIV, BC affected, BC at risk, CC affected, and CC at risk) and also by genetic versus nongenetic disease. Calculations changing the definition of genetic disease to include those with a personal or family history of cancer were also performed for each question, but the results are not reported here because they generally did not differ from the results presented here in any significant way. Those variables that were not independent of the response (at $P < 0.05$) were considered possible predictors in regression analyses, as were two variables believed a priori to be important to the response in question: privacy level (open, neutral, or private; self-reported) and level of social disclosure (full, some, or no social disclosure; as measured by proxy by respondents' report of how many friends and neighbors knew about their condition: all, some, or none, respectively). Adjusted odds ratios were calculated with logistic regression models when the outcome was binary (for example, yes or no). Ordinal logistic regression models (also known as proportional odds models) were used for calculating odds ratios for categorical outcomes since, in this study, the categorical outcomes all had an inherent ordering (for example, "agree," "neutral," or "disagree"). Because the outcomes reported here represented single items on the questionnaire, the regression models were all separate, single models that were not compared. Thus, adjustment for multiple comparisons was not necessary.

RESULTS

Experiences With Disclosure and Confidentiality

When asked about the disclosure of their condition to others, the vast majority of participants reported that their spouse or partner (>90%) and immediate family (91%) knew about their condition, but considerably fewer (47%) reported that their friends and neighbors knew. Subjects were also asked a series of questions about their experiences with confidentiality of their medical information. The percentages of "yes" responses to these questions by disease group are shown in Table I. Relatively few (8%) reported that their medical provider had shared information about them without their permission; these responses did not differ by disease group, as measured by the Pearson chi-square test. Participants' experiences did significantly differ by disease group with regard to whether they had discussed confidentiality with their provider, whether they had signed documents regarding confidentiality of their medical information, and whether a provider had ever withheld information to protect them. In each case, those with HIV answered affirmatively more often than those in other disease groups. However, when responses were broken down by genetic versus nongenetic disease, no significant differences were seen for any of these questions.

Logistic regression models (adjusted for privacy level and level of social disclosure) were tested for each of these questions. Those with no social disclosure (OR = 2.14; $P = 0.048$), those with HIV (OR = 2.95; $P = 0.030$), and those under 40 (OR = 2.38; $P = 0.011$) were significantly more likely than those with full social disclosure, those with CF, and those who were 50 years old or older, respectively, to report having discussed confidentiality with their provider. Those with no social disclosure were less likely to report having signed confidentiality documents (OR = 0.40; *P* = 0.008), while respondents with HIV were much more likely than those with CF to report having signed such documents (OR = 2.96; *P* = 0.017). Females were less likely than males to report that providers had given information about them to others without their permission (OR = 0.44; *P* = 0.001; adjusted for age). Finally, those with SCD were significantly less likely than the reference group CF (OR = 0.24; *P* = 0.008) to report that a provider refused to give out information to protect them (data not shown).

Beliefs About Confidentiality of Medical Records

Table II shows the percentages of “likely” (versus “not sure” and “unlikely”) responses to a variety of scenarios in which family members and others might get medical information about them. Respondents believed that family members were not as likely as those outside the family (such as health insurers) to get such information, either without their knowledge or without their permission. Only the responses to questions regarding employers’ access to information about them differed by disease group, and none differed by genetic versus nongenetic conditions.

Ordinal logistic regression models that were adjusted for privacy level and level of social disclosure were tested for each of these questions. Parents were less likely than affected adults to think family members could get information about them without their knowledge (OR = 0.52; *P* = 0.002; adjusted for relationship to self and age) and those giving either some or no social disclosure were move likely than were more likely than with giving full disclosure to think it likely that immediate family could get medical information without their permission (OR = 1.68, *P* = 0.016, and OR = 1.92, *P* = 0.047, respectively; adjusted for disease group). Finally, those with SCD, HIV, BC, and CC and parents were significantly less likely and those in the higher-age groups (over 40) were significantly more likely to think employers could get medical information about them, either without their knowledge or without their permission (data not shown).

Respondents were also given a list of different medical conditions and asked, for each, whether records pertaining to that condition should be kept in a special file or in the person’s general medical file, with the explanation that it might be beneficial for doctors to have the information in a general file when treating a patient but that confidentiality might be protected if the information was in a special file. The percentages of respondents, by disease group, who believed that medical records pertaining to various conditions should have special privacy protections (versus being kept in the same general file as all other medical records) are shown in Table III. Generally, respondents were most likely to cite abortion history, mental health history, and HIV status as deserving of special protections. However, the responses generally did not significantly differ by disease group, except in the cases of HIV status (with those in HIV group much more frequently and those in the CC groups much less frequently citing HIV as deserving such protections), CF, and SCD. The only disease for which beliefs about special protections differed significantly by genetic versus nongenetic disease was a hereditary disease, Huntington disease. However, it was the respondents with nongenetic conditions who were slightly more likely than those with genetic conditions (16.2% vs. 13.6%) to think those records should be kept in a separate file.

Generally, logistic regression with these responses as outcomes and privacy level and level of social disclosure as covariates yielded few interesting results. Those with higher education levels (college or above) were more than twice as likely as those without high school degrees to believe mental health history and drug/alcohol history deserved special protections (adjusted for race and income levels; data not shown). African Americans were twice as likely as Caucasians (OR = 2.04; $P = 0.037$; adjusted for disease group, age, marital status, race, and income) to believe that HIV deserved special protections. Finally, those in the higher income groups were more likely to cite SCD and genetic test results as conditions requiring special protections (data not shown).

Because we were concerned that respondents were merely more likely to feel that their own disease deserved special privacy protections than were respondents with other diseases, we examined this issue with a series of contingency tables, in which the percentages of positive responses of those with the condition and those without were compared by the Pearson chi-square test for each of the conditions. There was an overall trend for those with a particular disease to feel that their disease deserved special protections more often than those without the disease. However, this trend was reversed in respondents with BC and CC, and these trends were only significant for HIV and BC (data not shown). To examine whether how respondents with HIV and BC felt about their own disease was different from how they felt about other diseases, pairwise comparisons of coefficients from logistic regressions with only disease group as a covariate were made for HIV and BC with a *t*-test corrected for multiple comparisons. By these analyses, only those with HIV felt their own disease should be kept private more than other diseases.

Attitudes Toward Family Member vs. Provider/Employer/Insurer Confidentiality and Law

The percentages of “agree” (versus “neutral” and “disagree”) responses to a series of statements involving medical provider/insurer/employer and family member confidentiality are shown in Tables IV and V, respectively. Within provider/insurer/employer confidentiality, the only statement for which the level of agreement differed significantly between the disease groups or by genetic versus nongenetic disease groups (87.5% vs. 75.3% agreement, respectively) was “I don’t mind if my medical provider gives medical information about me to other providers when it is for my benefit.” Those at risk for cancer (either BC or CC) agreed with this statement much less often than did those in the other disease groups; this significance held in regression analyses. For the statements involving family member confidentiality, although the results generally did not differ significantly between disease groups, those in the HIV group agreed much less often than the other groups with the statements “If someone wanted to know whether his or her parent has a hereditary condition, he or she should be able to find out” and “It is the responsibility of family members to share information on hereditary conditions that might affect other family members.” Interestingly, responses did not differ by genetic versus nongenetic disease groups for any of these statements, even those related to hereditary conditions.

In ordinal logistic regression analyses (adjusted for privacy level and level of social disclosure), those with BC were less likely to agree that people are frequently harmed when medical providers release information about them (OR = 0.45; *P* = 0.041; adjusted for marital status and income), yet they were also less likely to think providers keep their promises about keeping information confidential (OR = 0.37; *P* = 0.010; adjusted for income) than the reference group CF. Those in higher-income groups (>$20,000 per year) were also significantly less likely to agree that providers keep such promises. Those who were at risk for disease (versus affected) were less likely to agree that providers should be punished for releasing patients' information to other providers (OR = 0.60; *P* = 0.040; adjusted for sex) and more likely to agree that they should be punished for releasing information to health insurance companies (OR = 1.84; *P* = 0.041) without their permission. Finally, older subjects (50 years of age or older) were more likely than those under 40 to agree that they would not mind if a provider gave their medical information to a health insurance company without their permission (OR = 2.04; *P* = 0.040; data not shown).

Ordinal logistic regression with privacy level and level of social disclosure as covariates also showed that younger adults (<40; OR = 1.85; *P* = 0.001) and unemployed persons (OR = 2.16; *P* = 0.001) were more likely than those 40–49 and full-time employees to agree that they would not mind if their doctor gave medical information to family members without their permission. Parents were less likely than affected persons to agree that people should be allowed to get medical information about a person in their family without that person's permission (OR = 0.44; *P* = 0.002). The oldest subjects (50 years of age or older) were more likely to agree that someone should be able to find out whether his or her parent has a hereditary condition than those under 40 (OR = 1.78; *P* = 0.047). Finally, those with no social disclosure (versus full disclosure) were significantly less likely to agree that family members are responsible for sharing information on hereditary diseases that might affect other family members (OR = 0.22; *P* = 0.001; data not shown).

Finally, Table VI shows the percentages of respondents, by disease group, that agreed with several statements regarding the law and confidentiality. The majority agreed that there should be laws to ensure that others are not able to obtain medical information about them without their permission; only 16% overall believed that certain people should be allowed to get information from their file, with or without permission. About half agreed that there already are laws that adequately limit access to medical information. None of the responses presented in Table VI differed by disease group or by genetic versus nongenetic disease.

In logistic regression, unemployed persons (OR = 1.76; *P* = 0.018) and African Americans (OR = 1.70; *P* = 0.028) were more likely than full-time employees and Caucasians, respectively, to agree that there should be laws that allow certain people access to their files, with or without permission (adjusted for privacy level and social disclosure). African Americans were also more likely than Caucasians to agree that there are already laws that do a good job of limiting access to information (OR = 2.05; *P* = 0.026), although those in the higher-age groups and those who rated themselves private were significantly less likely to agree with this statement (adjusted for social disclosure, disease group, marital status, education level, income, and employment status; data not shown).

DISCUSSION

Although relatively few study participants (8%) reported that a medical provider had actually given out information about them to someone else without their permission, several of the responses indicate that participants believed it quite likely that others (especially people outside the family, such as health insurers and hospital workers) could get information about them, either without their knowledge or without their permission, and the majority believed that there should be laws that keep people from getting information about them unless they give permission. Only about half believed that current laws already do a good job of limiting access to information.

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Despite these feelings, and although two-thirds reported signing confidentiality documents concerning their medical records, only about one-quarter of participants reported having discussed confidentiality with their provider. Younger participants, those with HIV, and those who had not told friends and neighbors about their condition were most likely to have discussed confidentiality with their providers. Participants indicated a fairly high level of trust regarding their medical providers, with about three-quarters believing that providers keep their promises about confidentiality and nearly 80% indicating that they did not mind if their providers release information if it is for their benefit. However, similar proportions believed doctors should be punished if they release information to other providers, health insurance companies, or employers, indicating that although patients believe strongly that they should be in control of access to their own records, they generally trust their providers to release their information to the proper people and for the right reasons.

This trend of participants not minding if others obtain medical information about them as long as they were in control of that information was also seen with family members. Although the vast majority reported that their spouse/partner and immediate family knew about their condition, only about 30% agreed that they would not mind if a provider gave information to family members without their permission, and more than half agreed that providers should be punished if they do so. Thus, although health professionals are encouraged to break the usual rules of confidentiality and inform family members against a patient’s wishes when a disease is serious, likely to occur, and preventable or treatable [American Society of Human Genetics Social Issues Subcommittee on Familial Disclosure, 1998], it seems that most patients are not in favor of this policy. At the same time, participants overwhelmingly believe persons with hereditary conditions should disclose such information to others in their family if the condition could affect them. Moreover, participants clearly have some ambivalence about the degree to which familial disclosure by others is appropriate, given that only a small minority believed someone should be able to get information about a family member without their permission, but nearly 70% believed someone should be able to find out if his or her parent has a hereditary condition.

Most measures here did not differ by whether participants had genetic versus nongenetic conditions, but in the few cases in which there was a difference, it was generally those with nongenetic diseases who were more concerned about the confidentiality issue in question. Moreover, those with genetic conditions did not believe that their diseases deserved more special protections than other diseases. In fact, respondents more frequently indicated possibly stigmatizing conditions such as abortion history, mental health history, drug/alcohol history, HIV infection, and sexually transmitted diseases as needing special protections. Indeed, where trends in the data occurred, they followed differences in characteristics of participants other than whether their condition was strictly hereditary. For example, those with HIV were most concerned and those with BC were least concerned about confidentiality; African Americans were less concerned than Caucasians; those with higher levels of education and income were more concerned than those in the lower levels; and males were more concerned about confidentiality than were females.

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There are several limitations to this study. First, HIV generally has been viewed as a more stigmatizing condition than the other conditions included in this study, and results from this group may have had undue influence on some of the results we observed (especially when results were broken down by genetic versus nongenetic disease groups). Also, it is unknown whether or to what extent participants considered the nongenetic diseases in this study to be hereditary, but we believe that we controlled for this problem to the best of our ability by examining several breakdowns of genetic versus nongenetic for each question reported. Another theoretical limitation of this study is that although we performed detailed interviews of nearly 600 participants, we cannot rule out the possibility that the six conditions included in this study may not be completely representative of genetic and nongenetic conditions, which are imprecisely defined here and, possibly, impossible to distinguish. Finally, there were no items on our survey concerning specifically how subjects would feel if their family members disclosed possibly identifiable information about themselves to a physician or research study investigator as part of their family history, an issue that has recently been discussed by medical ethicists [Botkin, 2001].

Despite these limitations, it is clear that the majority of subjects in this study, regardless of what type of condition they had, felt that release of medical information to others for the appropriate reasons was acceptable, but generally only when they had given their permission. Subjects indicated that this permission was essential even with family members, the majority of whom knew about the subject’s condition. When asked about hereditary conditions, subjects overwhelmingly felt that family members should be able to find out about such

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conditions but that the affected person, not a health professional, should be responsible for disclosing that information to other family members.

The results presented here indicate that persons with serious genetic and nongenetic medical conditions both feel strongly about the confidentiality of their medical information. However, this study provides no evidence that patients feel more strongly about the confidentiality of their genetic or familial information than they do about any of their medical information, supporting the argument that genetic information is not different from other medical information [Beckwith and Alper, 1998; Gostin and Hodge, 1999], at least to the patient. Many recent state and federal laws mandating confidentiality protections [Annas, 2001] have relied heavily on the assumption that genetic information is inherently different from other medical information, but even laws aimed at mandating the protection of patients from genetic discrimination are complicated by the fact that genetic and nongenetic tests for multifactorial conditions are often indistinguishable [Alper and Beckwith, 1998]. Our results indicate that this extensive policy focus on providing special protections for medical genetic information as distinct from other medical information may be unwarranted.

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TABLE I

Experiences With Disclosure and Confidentiality[★]

Text of question	CF	SCD	DM	HIV	BC-A	BC-AR	CC-A	CC-AR	Total
Have you ever discussed confidentiality with your healthcare provider? (n = 591)[a]	17.7	24.7	16.5	45.9	24.0	24.4	15.2	18.0	24.2
Have you ever signed any documents regarding the confidentiality of your medical records? (n = 573)[a]	74.8	51.0	65.4	84.9	66.0	68.9	56.5	60.0	66.7
Did a medical provider ever give medical information about you to anyone else without your permission? (n = 587)	9.52	9.88	5.68	11.0	10.2	6.98	6.82	4.25	8.35
Has there ever been a time when a medical provider refused to give medical information about you to someone else in order to help you in some way? (n = 587)[a]	6.82	0.00	4.44	19.5	10.0	9.09	6.67	0.00	7.22

[★] Shown are the percentages of respondents answering yes to the indicated questions. The total number of responses for each question is shown in parentheses. DM, diabetes mellitus; A, affected; AR, at risk.

[a] Overall Pearson chi-square by disease group; *P* < 0.001.

TABLE II

Beliefs About Likelihood of Unauthorized Access to Medical Records[★]

Text of question	CF	SCD	DM	HIV	BC-A	BC-AR	CC-A	CC-AR	Total
How likely is it that members of your immediate family could get medical information about you…									
Without your knowledge (n = 580)	33.3	31.6	44.1	27.4	38.8	40.0	50.0	37.5	36.6
Without your permission (n = 578)	16.5	26.8	30.7	12.6	25.0	28.9	26.7	26.0	23.4
How likely is it that health insurers could get medical information about you…									
Without your knowledge (n = 539)	73.3	58.2	72.0	63.6	85.4	75.0	77.3	71.1	70.5
Without your permission (n = 547)	62.3	53.7	59.4	59.7	71.7	54.6	65.2	51.1	59.4
How likely is it that employers could get medical information about you…									
Without your knowledge (n = 344)[a]	38.7	14.6	46.0	23.5	38.5	44.7	60.9	43.3	37.2
Without your permission (n = 339)[a]	31.2	16.7	41.0	23.5	25.6	37.8	58.3	34.5	32.2
How likely is it that public health authorities could get medical information about you…									
Without your knowledge (n = 573)	56.8	61.1	56.0	57.9	70.0	53.3	54.4	59.6	58.5
Without your permission (n = 568)	45.2	50.5	52.0	51.6	59.2	46.7	51.2	52.1	50.7
How likely is it that hospital workers could get medical information about you…									
Without your knowledge (n = 580)	71.1	75.0	74.3	70.8	78.0	77.8	73.9	83.7	74.7
Without your permission (n = 580)	57.3	60.2	69.7	62.1	70.0	75.6	59.6	74.0	64.8

[★] Shown are the percentages of respondents reporting that the indicated events were “likely” to occur. The total number of responses for each question is shown in parentheses. DM, diabetes mellitus; A, affected; AR, at risk.

[a] Overall Pearson chi-square by disease group; $P < 0.05$.

TABLE III

Beliefs About Special Privacy Protections for Medical Records[★]

Special privacy protections for	CF	SCD	DM	HIV	BC-A	BC-AR	CC-A	CC-AR	Total
Abortion history (n = 589)	65.4	69.7	71.6	63.2	68.0	66.7	78.7	70.0	68.6
Mental health history (n = 589)	60.4	50.5	68.3	58.3	66.0	64.4	55.3	60.0	60.1
HIV/AIDS (n = 589)[a]	53.5	61.6	52.0	77.9	50.0	40.0	29.8	38.0	54.0
Genetic test results (n = 256)	48.2	40.8	66.7	0.00	46.9	51.1	34.4	54.0	46.5
Drug/alcohol history (n = 590)	49.5	32.3	48.0	44.8	50.0	57.8	29.8	46.0	44.4
Sexually transmitted disease (n = 589)	53.5	39.8	39.2	50.0	52.0	40.0	29.8	40.0	44.0
BC (n = 573)	22.8	39.4	31.4	34.4	14.3	30.2	23.9	21.6	29.0
CC (n = 557)[b]	19.4	32.3	24.0	34.4	12.2	18.6	13.6	16.2	23.5
Family history of cancer (n = 250)	19.2	22.5	0.00	0.00	14.3	24.4	13.8	27.1	20.4
SCD (n = 590)	20.8	24.2	21.6	24.0	6.00	17.8	19.2	14.0	19.8
CF (n = 589)[b]	22.8	13.1	22.6	16.8	12.0	15.6	14.9	18.0	17.7
Huntington disease (n = 587)	12.0	15.2	20.6	18.1	8.00	13.3	12.8	18.0	15.5
Diabetes (n = 590)	11.9	14.1	15.7	10.4	4.00	13.3	12.8	10.0	12.0
Cholesterol level (n = 590)	10.9	9.09	15.7	8.33	8.00	13.3	12.8	6.00	10.7
Heart disease (n = 590)	5.94	10.1	12.8	13.5	2.00	15.6	8.51	14.0	10.3

[★] Shown are the percentages of respondents reporting that the indicated conditions deserved “special protections.” The total number of responses for each question is shown in parentheses. DM, diabetes mellitus; A, affected; AR, at risk.

[a] Overall Pearson chi-square by disease group; $P < 0.001$.

[b] Overall Pearson chi-square by disease group; $P < 0.05$.

TABLE IV

Attitudes Toward Medical Provider, Insurer, and Employer Confidentiality*

Text of question	CF	SCD	DM	HIV	BC-A	BC-AR	CC-A	CC-AR	Total
I don't mind if my medical provider gives medical information about me to other providers when it is for my benefit (n = 580)[a]	88.1	86.9	84.3	70.4	80.0	51.1	93.6	66.0	79.4
People frequently are harmed when medical providers release information about them (n = 591)	23.0	32.7	17.3	43.9	14.3	35.6	36.2	26.0	28.6
When medical providers promise they will keep information confidential, they usually keep these promises (n = 591)	77.2	70.7	72.6	78.8	56.0	75.6	66.7	72.0	72.4
The law should punish medical providers who give patients' information to other providers without permission (n = 593)	70.3	68.4	58.7	77.6	68.0	62.2	66.0	62.0	67.3
I don't mind if my health care provider gives medical information about me to my health insurance company without my permission (n = 592)	9.00	19.2	20.6	20.2	22.0	8.89	23.4	18.0	17.6
Doctors should be punished if they release medical information about patients to health insurance companies without permission (n = 597)	73.3	72.7	69.6	76.0	62.5	82.2	66.0	81.6	72.9
Employers should be allowed to get medical information about people without their permission (n = 590)	2.97	5.05	2.97	2.02	4.08	0.00	8.51	2.04	3.39
Doctors should be punished if they release medical information about patients to employers without their permission (n = 590)	80.2	79.8	79.2	82.7	75.5	86.7	83.0	76.0	80.3

*Shown are the percentages of respondents reporting that they agree with the statements indicated. The total number of responses for each question is shown in parentheses. DM, diabetes mellitus; A, affected; AR, at risk.

[a] Overall Pearson chi-square by disease group; $P < 0.05$.

TABLE V

Attitudes Toward Family Member Confidentiality[★]

Text of question	CF	SCD	DM	HIV	BC-A	BC-AR	CC-A	CC-AR	Total
I don't mind if my doctor gives medical information about me to family members without my permission (n = 593)	32.7	27.3	29.4	22.2	30.0	20.0	34.0	30.0	28.2
People should be allowed to get medical information about a person in their family without that person's permission (n = 588)	6.00	9.09	12.9	7.07	16.3	13.3	17.0	14.6	10.9
If someone wanted to know whether his or her parent has a hereditary condition, he or she should be able to find out (n = 586)[a]	68.0	70.7	72.3	42.3	82.0	67.4	83.0	79.6	68.3
Doctors should be punished if they release medical information about a patient to other members of the patient's family without permission (n = 585)	54.5	59.8	50.5	62.2	42.9	64.4	42.6	49.0	54.4
It is the responsibility of family members to share information on hereditary diseases that might affect other family members (n = 589)[a]	96.0	87.6	96.0	80.8	93.9	100	100	98.0	92.7

[★] Shown are the percentages of respondents reporting that they agree with the statements indicated. The total number of responses for each question is shown in parentheses. DM, diabetes mellitus; A, affected; AR, at risk.

[a] Overall Pearson chi-square by disease group; $P < 0.05$.

TABLE VI

Attitudes Toward Law and Confidentiality[★]

Text of question	**CF**	**SCD**	**DM**	**HIV**	**BC-A**	**BC-AR**	**CC-A**	**CC-AR**	**Total**
There should be laws that allow certain people to get medical information from my file, with or without my permission (n = 588)	12.9	19.2	10.9	25.0	16.0	11.1	12.8	14.3	15.8
There should be laws that make sure people can’t get medical information about me in any way unless I give permission (n = 583)	79.2	88.8	90.1	90.3	87.8	93.3	78.7	77.6	86.1
There are already laws that do a good job of limiting who can get information about my medical condition (n = 575)	44.8	56.1	45.9	57.7	35.4	40.0	35.6	27.1	45.7

[★] Shown are the percentages of respondents reporting that they agree with the statements indicated. The total number of responses for each question is shown in parentheses. DM, diabetes mellitus; A, affected; AR, at risk.