Educational Needs of Primary Care Physicians Regarding Direct-to-Consumer Genetic Testing

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Powell, K.P., Christianson, C.A., Cogswell, W.A., Dave, G., Verma, A., Eubanks, S., Henrich, V.C. (2012). Educational needs of primary care physicians regarding direct-to-consumer genetic testing. *Journal of Genetic Counseling, 21(3),* 469-478. doi: 10.1007/s10897-011-9471-9

The final publication is available at Springer via http://dx.doi.org/10.1007/s10897-011-9471-9

Abstract:

To assess the educational needs of North Carolina primary care physicians (PCPs) about direct-to-consumer (DTC) genetic testing, surveys were mailed to 2,402 family and internal medicine providers in North Carolina. Out of 382 respondents, 323 (85%) felt unprepared to answer patient questions and 282 (74%) reported wanting to learn about DTC genetic testing. A total of 148 (39%) were aware of DTC genetic testing. Among these, 63 (43%) thought DTC genetic testing was clinically useful. PCPs who felt either unprepared to answer patient questions (OR = 0.354, $p = 0.01$) or that DTC genetic testing was clinically useful (OR = 5.783, $p = 0.00$) were more likely to want to learn about DTC genetic testing. PCPs are interested in learning about DTC genetic testing, but are mostly unaware of DTC testing and feel unprepared to help patients with DTC testing results. Familiar and trusted channels that provide the information and tools PCPs need to help answer patient's questions and manage their care should be used when creating educational programs.

Keywords: Direct-to-Consumer | Genetic testing | Primary care providers | Genetic susceptibility Personalized medicine | Genetics in primary care | Educational needs

Article:

Introduction

In 2007, companies began offering personal genome tests for the prediction of common complex diseases and medication responses, based on genome-wide association study (GWAS) variants, over the internet (Offit *2008*). Some companies sell these tests directly to consumers without requiring consultation with a health care provider. On their websites these companies state that

they are not offering medical advice, diagnosis or treatment, and they recommend that consumers consult with their primary care physicians (PCPs) to discuss the results of their test before making medical decisions (23andMe *2011*; deCODEme *2011*; Pathway Genomics *2011*).

PCPs are the front line of medical care, and see patients at risk for, and affected by, common complex diseases, such as heart disease and diabetes (Feero *2008*). Many times, information about health decisions can be made over several visits, thereby forging a relationship over time. Patients tend to trust and value these relationships and seek out their PCPs opinions when making healthcare decisions. Because of this relationship, it's been suggested that PCPs are the appropriate providers to see patients who are identified at increased risk for common complex genetic diseases based on their family history or genetic test results (Burke and Emery *2002*; Guttmacher et al. *2001*).

Studies indicate that patients do seek out their PCPs to discuss their genetic test results and obtain the appropriate follow-up care (Burke *2004*; Holtzman and Watson *1997*; Miller et al. *2010*; Morren et al. *2007*) Additionally, there is evidence that patients are talking to their health care providers about personal genome testing (Kolor et al. *2009*; Ohata et al. *2009*; Powell et al. *2011*), and there is an expectation that PCPs will be able to answer questions about personal genome test results (McGuire et al. *2009*). In the 2008 DocStyles survey, over 40% of PCPs aware of personal genome testing offered directly to the consumer reported they had patients ask them questions, and 15% reported that patients had actually brought in test results (Kolor et al. *2009*). A similar study of PCPs in North Carolina found that almost 19% of PCPs aware of personal genome testing had a patient ask questions, and of those individuals, approximately 3% had a patient bring in their test results (Powell et al. *2011*). This suggests that PCPs may see an increase in questions about personal genome test results should this type of testing become more mainstream.

PCP's generalized lack of knowledge about genetics and the fact that they do not feel prepared to answer patient questions about genetic topics, including personal genome tests has been documented (Greendale and Pyeritz *2001*; Powell et al. *2011*; Suther and Goodson *2003*). In part, this could be the result of the dearth of formal genetics training in medical school and residency programs (Thurston et al. *2007*). Few medical schools are exposing their students to information about GWAS and the role that SNP testing plays in the identification of risk factors to genetic disease (Vence *2010*).

Calls to increase genetics and genomics education in medical school and residency programs have been made (Guttmacher et al. *2007*; Scheuner et al. *2008*; Thurston et al. *2007*; Vence *2010*) and guidelines and initiatives to do this have been created (American Academy of Family Physicians Core Educational Guidelines: Medical Genetics *2011*; Burke et al. *2002*; Reigert-Johnson et al. *2004*; Report VI - Contemporary Issues in Medicine: Genetics Education *2005*). However, it has been demonstrated that medical students do not to retain genetics knowledge over the course of their medical school career (Baars et al. *2005*; Greb et

al. *2009*; Ling et al. *2008*; Swanson et al. *1996*). Retention of knowledge regarding genetics may be further eroded by the fact that PCPs are more likely to see patients with common conditions such as heart disease or diabetes than those who have single gene disorders (Feero *2005*). The speed at which the science is changing and new tests are developed also makes it difficult for PCPs to stay current in genetics.

Several studies have evaluated education programs aimed at improving health care provider's genetic knowledge (Bethea et al. *2008*; Burke et al. *2002*; Burke and Emery *2002*; Laberge et al. *2009*). However, these studies looked at genetics education in primary care (Burke et al. *2002*; Guttmacher et al. *2001, 2007*; Suther and Goodson *2003*), and not at personal genome testing. At this time, information is scarce about how personal genome testing offered directly to consumers is relevant to PCP practice, if PCPs want to learn about these tests, and what supports are needed when questions arise.

Purpose of the Present Study

A goal of this study was to assess the education needs of North Carolina PCPs about DTC genetic testing. Other aims were to ascertain 1) PCPs' preference for delivery of educational materials, 2) barriers to PCPs' participation in a continuing education program and 3) PCPs' preference for topics to include in an educational program on DTC genetic testing.

Methods

Participants

A convenience sample of family physicians and internists who were members of the North Carolina Medical Society (NCMS) were recruited to participate (Powell et al. *2011*). The NCMS is the state's largest physician organization with more than 12,000 members (North Carolina Medical Society *2011*).

Survey Development

A novel survey consisting of 30 questions was created to meet the goal of this project. A description of personal genome testing was adapted from the 2008 DocStyles survey developed by the Centers for Disease Control and Prevention (CDC), and provided in the introduction. It read: "Genetic tests that scan a person's entire genetic makeup for potential health risks are currently being marketed directly to consumers by several different companies (e.g., 23andMe, deCODEme, Navigenics)." Respondents were told that the term 'DTC genetic test' would be used as a shorthand way to describe this service.

Four of the 30 questions asked how PCPs would want to be educated about DTC genetic testing (Appendix A). The remainder of the questions asked about awareness, experience, opinions, preparedness to answer questions about DTC genetic testing and demographics (Powell et al. *2011*). The survey was piloted with 10 family medicine and internal medicine physicians

practicing in Greensboro, North Carolina. No modifications were made. This study was approved by The University of North Carolina at Greensboro's Institutional Review Board.

Procedures

The physicians and surveys were numbered and a unique ID was created. Cover letters, surveys, informed consent, and a self-addressed stamped envelope (SASE) were mailed to all physicians with confirmed addresses (Powell et al. *2011*). While no compensation was provided to respondents, they were offered a copy of the results once the survey was completed (Dillman et al. *2009*; Lydeard *1996*). Physicians completing the survey online were asked to enter their survey number to avoid duplication. When a survey was returned, the physician's name and address were deleted from the key. Two reminders were sent to non-responders at three-week intervals. The first reminder was a postcard which referenced the online link. The second reminder contained a cover letter, survey and SASE. Data collection occurred between January and May, 2010.

Statistical Analysis

Information from the returned surveys was entered into Zoomerang, an on-line survey collection tool. Data analysis was conducted using PASW Statistics version 18.0 (Chicago, IL). The respondents' personal characteristics and survey characteristics relating to self-reported preparedness to answer questions, desire to learn more, and how they want to learn about DTC genetic testing were described with frequencies and percent's. The ages of participants were collected within five categories: ≤30, 31-40, 41-50, 51-60, and >60. The age variable was collapsed into two categories based on the participant's experience. The variables ≤30 and 31-40 were collapsed to ≤40 (less experienced PCPs), the variables 41-50, 51-60 and >60 were collapsed to ≥41 (more experienced). Board specialty was dichotomized into family medicine and internal medicine and work setting was dichotomized into private practice and other. Responses to the dependent variable ('Would you like to learn more about DTC genetic testing?') were categorized yes and no.

All bivariate associations between physicians' personal and survey characteristic variables and participant's interest in education about DTC genetic testing were calculated using cross-tabulations. Odds ratios and confidence intervals (CI) at 95% were calculated using standard procedures to assess determinants of interest in education about DTC genetic testing. For the outcome variable, the initial model was formulated by including all of the covariates provided in Tables 1 and 2. In order to reduce the initial model to the final reduced model, odds ratio (OR) estimates were used for all personal characteristics that were shown to be predictors of participants' interest in education about DTC genetic testing. Covariates that were not statistically significant predictors of interest in education were eliminated from the full model using a step-wise forward regression procedure. Based on a previous analysis, age and years in practice were found to be significantly correlated (Pearson $r = 0.721$, $p = 0.00$), therefore years in

practice was eliminated from the model. The aim of this methodology is to identify the strongest simplified model of respondents' personal characteristics associated with the participant's interest in education about DTC genetic testing. Multivariate adjusted ORs and their 95% confidence interval (CI) were determined by exploring log ORs from the multivariate logistic regression using a forward stepwise likelihood ratio model. Missing data were excluded from the analyses where appropriate.

Table 1 Personal characteristics of respondents ($N = 382$)[a]

Personal characteristics	**Total**	
	N (378)	**%**
Gender		
Female	115	30.4
Male	263	69.6
Age		
≤40 years old	153	40.9
>40 years old	221	59.1
Board specialty[b]		
Family medicine	214	56.8
Internal medicine	153	40.5
Other	10	2.7
Work setting		
Academic medical center or medical school	34	9.0
Medical center not affiliated with university	9	2.4
Community hospital	23	6.1
Private practice	272	72.0
HMO	0	0
Other	40	10.6

[a]Totals do not sum to the sample size due to missing data [b]Totals include double boarded specialty

Table 2 Awareness of PCPs (N = 382), perceived utility and preparedness about DTC genetic testing among those aware of testing

Self-reported Awareness of PCPs	**N**	**%**
Heard or read about DTC genetic testing		
Yes	148	38.7
No	234	61.3
Clinical utility DTC genetic testing among those who are aware		
Feel that DTC testing is clinically useful		
Yes	63	42.6
No	85	57.4
Rating of clinical usefulness of DTC genetic testing [a,b]		
Very useful	3	5.1
Useful	4	6.8
Somewhat useful	50	84.7
Not useful	2	3.4
PCPs rating on likelihood that DTC test results would influence patient care [b]		
Very likely	7	4.8
Likely	50	34.0
Unlikely	70	47.6
Very unlikely	20	13.6
Preparedness about DTC genetic testing[b]		
PCP preparedness about genetic testing		
Yes	57	15.0
No	323	85.0

[a]Frequency is based on the number of PCPs who feel that DTC testing is useful; [b]Totals do not sum to the sample size due to missing data

Results

Survey Characteristics

As per the eligibility criteria, surveys were sent to 2,402 PCPs in North Carolina. Fifty surveys were 'returned to sender', resulting in 2,352 eligible respondents. In total, 397 surveys were returned to the researchers. Surveys were excluded from the final analysis if they were returned blank (n = 10) or the PCP was retired (n = 5), resulting in 382 completed surveys. The response rate for usable surveys in this study was 16.2% (382/2,352).

Respondents had the option of returning the survey by mail, fax, or completing it on-line. Of the surveys completed, 95.3% were returned by mail (n = 364) and 4.7% were completed on-line (n = 18). No respondents returned the survey by fax. Respondent demographics are in Table 1. A total of 382 respondents who completed and returned the survey were included in the final

analysis. A post-hoc analysis was conducted to determine the statistical power given the sample size of 382 which was 0.80.

Sample Demographics

Males accounted for two thirds of the respondent pool (69.6%, $n = 263$). More than half were >40 years old (59.1%, $n = 221$). Similarly, more than half of the respondents (56.8%, $n = 214$) were boarded in family medicine. Most of the respondents (72%, $n = 272$) worked in a private practice setting with an average of 21.8 (SD = 11.7) years in practice as a physician.

Awareness, Experience and Opinions of DTC Genetic Testing

As described previously, most respondents (61.3% $n = 234$) had never heard or read about DTC genetic testing (Table 2). Of those who were aware of DTC genetic testing (38.7%, $n = 148$), 18.9% ($n = 28$) had patients ask questions about DTC testing (mean = 3 patients) and 3% ($n = 5$) had patients bring in DTC test results (mean = 2 patients). Four of the five providers indicated that they did not change patient care because there were no medical guidelines to follow or the test indicated that the patient was not at increased risk. One provider recommended lifestyle changes such as dietary changes and supplements (Powell et al. *2011*). None of the providers indicated they referred a patient to a specialist based on their test results.

Among aware respondents ($n = 148$), almost half (42.6%, $n = 63$) thought that testing was clinically useful when formulating medical management plans. The most frequently mentioned benefits were the ability to: 1) offer screening tests (e.g. mammograms, colonoscopies, EKG) *at an earlier age* to individuals at an increased risk and, 2) offer these screening tests *more frequently* to individuals who are found to be at an increased risk (Powell et al. *2011*). A majority of the respondents (85%, $n = 323$) did not feel prepared to answer their patient's questions regarding DTC genetic testing. In determining educational preferences of PCPs, bivariate associations were significant for PCPs who perceived clinical usefulness of DTC genetic testing. PCPs who were less prepared to answer questions about DTC genetic testing were also more likely to want to learn more about DTC genetic testing (Table 3). A multivariate logistic regression using a stepwise forward likelihood ratio indicated that PCPs perceived clinical usefulness of DTC genetic testing [OR = 5.783 (2.261, 14.789), $p = .00$] and PCPs preparedness to answer questions about DTC genetic testing [OR = 0.354 (0.149, 0.839), $p = .01$] were significant predictors of PCPs desire to learn more about DTC genetic testing. In order to further explore the interactions and impact of these two significant predictors on PCP's desire to learn more, bivariate analyses were conducted. No significant associations were found between PCP's perceived clinical usefulness and preparedness to answer questions about DTC testing (i.e. there was no significant overlap).

Table 3 Bivariate analysis – determinants of education of PCPs about DTC genetic testing

Participant characteristics	**DBP odds ratio (95% CI)**

Gender	
Female (reference)	--
Male	0.869 (0.519, 1.453)
Age	
≤40 years old (reference)	--
>40 years old	0.954 (0.591, 1.540)
Board specialty	
Family Medicine (reference)	--
Internal Medicine	0.945 (0.590, 1.514)
Awareness of DTC genetic testing	
No (reference)	--
Yes	0.797 (0.496, 1.280)
Perceived clinical usefulness of DTC genetic testing	
No (reference)	--
Yes	5.783* (2.261, 14.789)
Preparedness to answer questions about DTC genetic testing	
No (reference)	--
Yes	0.354* (0.149, 0.839)

*Significant at $p < 0.05$

Desire to Learn About DTC Genetic Testing

Approximately three fourths of the participants (73.8%, $n = 282$) reported that they wanted to learn more about DTC genetic testing (Table 4). The most common reasons PCPs did *not* want to learn more about DTC genetic testing included: (1) They would learn more if DTC genetic testing came up during a patient's visit, (2) They did not think that their patients would ask about DTC genetic testing and (3) They do not believe that DTC genetic testing will have a significant impact on the provision of health care in the next 10 years/before they retire. The top three topics individuals reported wanting to learn more were: (1) interpreting the results; (2) evidence-based guidelines to manage risks identified by the DTC genetic test results; and, (3) the various DTC genetic tests offered by the private companies. Twenty five 'Other' responses were written in and could be placed into the following categories: Discrimination/privacy issues ($n = 5$), quality assurance ($n = 5$), cost of testing ($n = 5$), general comments ($n = 5$), legislation ($n = 3$), testing of minors ($n = 1$), and availability of non-vendor counseling ($n = 1$). Furthermore, journals (68.4%, $n = 193$), information sessions at professional meetings (62.0%, $n = 175$), and trusted internet websites (42.1%, $n = 119$) were cited as the three most common media through which PCPs wanted to learn more about DTC tests (Table 4). 'Other' responses included: uptodate.com ($n = 2$), podcasts ($n = 1$), dinner meetings/programs ($n = 1$), weekly conferences with course objectives ($n = 1$) and non-vendor based brochures ($n = 1$). Bivariate associations between PCP's preparedness and top three areas for educational preferences were not statistically significant. There were no differences in educational preferences between the PCPs who had patients bring in test results and those who did not.

Table 4 Bivariate analysis – determinants of education of PCPs about DTC genetic testing

Participant characteristics	**DBP odds ratio (95% CI)**
Gender	
Female (reference)	--
Male	0.869 (0.519, 1.453)
Age	
≤40 years old (reference)	--
>40 years old	0.954 (0.591, 1.540)
Board specialty	
Family Medicine (reference)	--
Internal Medicine	0.945 (0.590, 1.514)
Awareness of DTC genetic testing	
No (reference)	--
Yes	0.797 (0.496, 1.280)
Perceived clinical usefulness of DTC genetic testing	
No (reference)	--
Yes	5.783* (2.261, 14.789)
Preparedness to answer questions about DTC genetic testing	
No (reference)	--
Yes	0.354* (0.149, 0.839)

*Significant at $p < 0.05$

Discussion

This study is among the first to look at the educational needs of PCPs whose patients ask questions about, or bring in test results from, personal genome DTC genetic testing. It highlights the lack of preparedness on the part of PCPs to answer questions about DTC genetic testing and their interest in learning more about this topic.

This study found that 38.7% of providers were aware of DTC genetic testing. Previous studies have found similar awareness rates among PCPs about DTC genetic testing (Kolor et al. *2009*). Lower awareness rates of DTC genetic testing, in part, could be a result of a low demand for DTC genetic testing in North Carolina, which has a relatively low median household income (41st in the nation) (2009 by the numbers *2009*; US Census Bureau *2009*; Pollack *2010*; Wright and Gregory-Jones *2010*).

DTC genetic testing topics that PCPs want to learn more about, as well as the barriers to learning more, are similar to the educational needs and barriers for general genetics. This study found that barriers to learning more about DTC genetic testing included a perceived lack of clinical utility and the belief that test results would have little to no impact to primary care practice. These issues are also barriers to the utilization of general genetics within primary care (Hayflick et al. *1998*; Mountcastle-Shah and Holtzman *2000*; Suther and Goodson *2003*). Some topics respondents wanted to learn more about pertaining to DTC genetic testing were unique to this

type of service. However, several similarities were found between what respondents wanted to learn about in regards to DTC genetic testing and general genetics. These include: guidelines for managing risk (de Bock et al. *1999*), costs of testing (Friedman et al. *1997*; Mountcastle-Shah and Holtzman *2000*) and ethical and legal issues including insurance discrimination (Friedman et al. *1997*; Watson et al. *1999*).

Primary care physicians who feel that DTC genetic testing is clinically useful and those who do not feel prepared to answer patient questions are particularly interested in learning more about DTC genetic testing. According to the results of a previous study, family practice physicians were more likely than internal medicine physicians to find DTC personal genome testing clinically useful (Powell et al. *2011*). Therefore, educational efforts could start by focusing on family practice physicians.

Educational programs could address the top priorities identified by PCPs, as well as whether clinical intervention based on DTC testing results is appropriate, and the benefits of referring patients for genetic counseling. Almost half of the providers who were aware of DTC genetic testing felt that the testing had clinical utility; however, clinical utility of DTC genetic testing varies based on the test and its analysis (US Government Accountability Office (*2010*). Therefore an education program should address how clinical utility is assessed and what evidence determines whether a test would be beneficial or change medical management (Field et al. *2010*). Lastly, five providers had an average of two patients each bring in test results (Powell et al. *2011*); however, none of them referred their patients to genetics, genetic counseling or another specialist. Therefore, the educational program could address what a referral to a genetic counselor could provide for their patient.

When planning an educational program, care should be taken to use the education channels that primary care providers routinely use (Burke and Emery *2002*). According to this study, efforts that will have the largest impact include writing articles for journals commonly read by PCPs and working with regional and national physician organizations to include presentations about DTC personal genome testing at their annual education conferences. These educational initiatives should give providers information about DTC personal genome testing, including the pros and cons of testing, and the tools they will need to help patients make informed decisions about this testing. PCPs need information on how to interpret test results and the legislation that protects against discrimination. They also need a list of the specific evidence-based guidelines they can follow to reduce disease risk.

This study suggests that PCPs are just-in-time learners who are driven by their need for information at a specific point in time. Therefore, educational initiatives should also include creating content about DTC personal genome testing on trusted websites that are used by primary care physicians. One such website mentioned in this study is uptodate.com (www.uptodate.com).

The results of this study identify potential roles for genetic counselors in the DTC genetic testing arena. Genetic counselors have a diverse skill set that lends itself to providing education about DTC genetic testing to primary care providers. In addition to providing genetic counseling to patients who have undergone DTC genetic testing, genetic counselors could educate primary care providers through the channels they want to be educated. The National Society of Genetic Counselors *2010* Professional Status Report indicates a majority of respondents have created educational materials (62%), created or organized a conference or workshop for healthcare professionals (23%), written an article in either peer-reviewed journal (20%) or newsletter (11%), or developed a brochure/pamphlet/video (17%) (National Society of Genetic Counselors *2010*). These experiences mirror the desired education that providers indicated they wanted for DTC genetic testing.

Limitations

Several aspects of this study may have limited generalizability of the findings because of the fact that this is a convenience sample of PCPs, and there was a low response rate (16.2%). However, this was not unexpected. The literature indicates that surveys of general practitioners generally achieve poor response rates (McAvoy and Kaner *1996*). Possible reasons for the low response rate include 1) lack of monetary incentives, 2) the mailed survey was four pages, printed front and back and appeared long, and/or 3) the topic was not of current clinical interest to the PCP population. Also, it cannot be determined how representative they survey respondents are of the general PCP population in North Carolina given that the only demographic charcteristic we could compare was gender. The gender demographics of this survey resembles the gender distribution of the NCMS membership (i.e. 66% and 73% males in family practice and internal medicine, respectively); these are the only demographic characteristics we could compare as the NCMS did not respond to requests for information concerning other demographic characteristics of their members. Additionally, the places North Carolina PCPs turn for information are similar to the results reported in other studies (Hofman et al. *1993*; Kolor et al. *2009*; Ohata et al. *2009*).

A second limitation of this study is that adults are just-in-time learners who are often driven by their need for information at a specific point in time. Therefore, we cannot determine if interest in this topic was generated by the survey itself, or if it represents a true interest of PCPs in learning more about personal genomic testing and its impact on their practice. Future studies could ask providers to rank topics related to DTC genetic testing relative to other topic areas outside of genetics and genomics (i.e. chronic disease management) in order to get an idea of their educational priorities.

A final limitation to the generalizability of this study is that patient demographics vary between states. The background of the typical patient in North Carolina may differ from those in other states within the region or throughout the US. Therefore, the experience of PCP’s in North Carolina as they relate to DTC genetic testing may vary from the experiences of PCP’s in other

states. Nevertheless, this study does provide preliminary findings for a larger comprehensive study.

Research Recommendations

This study focused solely on physicians. Other health care professionals, such as physician assistants and nurse practitioners who specialize in primary care, will also need to be queried about their educational needs surrounding DTC testing. These providers may have educational needs that are distinctly different from those of the physicians.

Conclusions

Primary care providers are interested in learning about DTC genetic testing. Topics of particular interest include interpreting test results, evidence-based guidelines to manage risks and information about the various DTC genetic tests. An educational initiative to improve knowledge about DTC genetic tests and address concerns about genetic discrimination may be most effective if it targets family practice physicians and uses familiar and trusted channels such as the publication of articles in journals read by PCPs, presentations at their regional and national meetings, and the development of web-based materials published on a trusted site. With their education, training and skills, genetic counselors are well poised to help develop, conduct and evaluate the educational efforts about DTC genetic testing for PCPs as well as all health care professionals. The goal is to give providers the information and tools they need to help patients make informed decisions about DTC genetic testing and to help them interpret their patients' test results and what they mean for medical management.

Appendix A: Questions Asking PCPs How They Want to be Educated About DTC Genetic Testing

1) Would you like to learn more about DTC genetic testing?
   a. Yes → SKIP to QUESTION 3
   b. No

2) If no, why are you not interested in learning more? Please, circle all that apply.
   AFTER ANSWERING THIS QUESTION, PLEASE END SURVEY.
   a. I do not think that my patients will be asking about DTC genetic testing
   b. I do not have time to learn more about DTC genetic testing
   c. I will learn more about DTC genetic testing if it comes up in a patient visit
   d. I am not interested in DTC genetic testing
   e. I do not think that DTC genetic testing will have any significant impact on the provision of health care in the next 10 years/before I retire

3) What would you like to learn about DTC genetic testing? Circle all that apply.
   a. The various tests being offered
   b. The different testing companies
   c. Services offered by the companies
   d. How to interpret the test results
   e. Where you can go to get more information about these tests
   f. Where you can go to get more information about what the test results mean
   g. Whether there are evidence-based risk management guidelines for people at risk for specific diseases
   h. What resources are available for patients who are thinking about pursuing DTC genetic testing
   i. What resources are available for patients who have had DTC genetic testing
   j. Other, please specify:_____

4) How would you prefer to learn about DTC genetic testing? Circle all that apply.
   a. Information sessions at a professional meeting
   b. Scientific or medical articles
   c. Through my professional organization
   d. Through a trusted Internet website
   e. Information sessions in my office with a sales rep
   f. Information sessions in my office with a genetic counselor or other health professional
   g. CME programs outside of professional meetings (e.g. web-based programs, CD-ROMS, etc)
   h. Booklets
   i. Brochures or pamphlets
   j. Magazine or newspaper articles
   k. TV
   l. Other, please specify: _____

References

2009 by the numbers (2009). *Nature medicine*, *15*(12), 1351–1352.

23andMe (2011). *23andMe terms of service*. Retrieved April 12, 2011, from www.23andme.com/legal/tos/

American Academy of Family Physicians Core Educational Guidelines: Medical Genetics. (2011). Retrieved September 22, 2010, from www.aafp.org/afp/990700ap/core.html

Baars, M. J. H., Scherpbier, A. J. J. A., & Schuwirth, L. W. (2005). Deficient knowledge of genetics relevant for daily practice among medical students nearing graduation. *Genetics in Medicine, 7*, 295–301.

Bethea, J., Qureshi, N., Drury, N., & Guilbert, P. (2008). The impact of genetics outreach education and support to primary care on practitioners confidence and competence in dealing with familial cancers. *Community Genetics, 11*, 289–294.

Burke, W. (2004). Genetic testing in primary care. *Annual Review of Genomics and Human Genetics, 5*, 1–14.

Burke, W., & Emery, J. (2002). Genetics education for primary care providers. *Nature Reviews, 3*, 561–566.

Burke, W., Acheson, L., Botkin, J., Bridges, K., Davis, A., Evans, J., et al. (2002). Genetics in primary care: A USA faculty development initiative.*Community Genetics, 5*, 138–146.

de Bock, G. H., Vliet Vlieland, T. P., Hageman, G. C., Oosterwijk, J. C., Springer, M. P., & Kievit, J. (1999). The assessment of genetic risk of breast cancer: a set of GP guidelines. *Family Practice, 16*(1), 71–77.

deCODEme (2011). *deCODEme service agreement*. Retrieved April 12, 2011, from www.decodeme.com/service-agreement

Dillman, D. A., Smyth, J. D., & Christian, L. M. (2009). *Internet, mail and mixed-mode surveys: The tailored design method*, 3rd edition. John Wiley & Sons, Inc.

Field, A., Krokosky, A., & Terry, S. F. (2010). Direct-to-consumer marketing of genetic tests: access does not reflect clinical utility. *Genetic Testing and Molecular Biomarkers, 14*(6), 731–732. doi:10.1089/gtmb.2010.1514.

Feero, W. G. (2005). Peas, priorities, and primary care: cultural competency starts at home. *Genetics in Medicine, 7*, 588–589.

Feero, W. G. (2008). Genetics of common disease: a primary care priority aligned with a teachable moment? *Genetics in Medicine, 10*, 81–82.

Friedman, L. C., Plon, S. E., Cooper, H. P., & Weinberg, A. D. (1997). Cancer genetics–survey of primary care physicians' attitudes and practices.*Journal of Cancer Education, 12*(4), 199–203. doi:10.1080/08858199709528489.

Greb, A. E., Brennan, S., McParlane, L., Page, R., & Bridge, P. D. (2009). Retention of medical genetics knowledge and skills by medical students.*Genetics in Medicine, 11,* 365–370.

Greendale, K., & Pyeritz, R. E. (2001). Empowering primary care health care professionals in medical genetics: how soon? How fast? *American Journal of Medical Genetics, 106,* 223–232.

Guttmacher, A. E., Jenkins, J. F., & Uhlmann, W. R. (2001). Genomic medicine: who will practice it? A call to open arms. *American Journal of Medical Genetics, 106,* 216–222.

Guttmacher, A. E., Porteous, M. E., & McInerney, J. D. (2007). Educating health-care professionals about genetics and genomics. *Nature Reviews, 8,* 151–157.

Hayflick, S. J., Eiff, M. P., Carpenter, L., & Steinberger, J. (1998). Primary care physicians' utilization and perceptions of genetics services.*Genetics in Medicine, 1*(1), 13–21.

Hofman, K. J., Tambor, E. S., Chase, G. A., Geller, G., Faden, R. R., & Holtzman, N. A. (1993). Physicians' knowledge of genetics and genetic tests. *Academic Medicine, 68,* 625–632.

Holtzman, N. A., & Watson, M. S. (1997). *Improving providers understanding of genetic testing,* Promoting safe and effective genetic testing in the United States: Final Report of the Task Force on Genetic Testing.

Kolor, K., Liu, T., St Pierre, J., & Khoury, M. J. (2009). Health care provider and consumer awareness, perceptions and use of direct-to-consumer personal genomic tests, United States, 2008. *Genetics in Medicine, 11,* 595.

Laberge, A. M., Fryer-Edwards, K., Kyler, P., Lloyd-Puryear, M. A., & Burke, W. (2009). Long-Term outcomes of the "genetics in primary care" faculty development initiative. *Family Medicine, 41,* 266–270.

Ling, Y., Swanson, D. B., Holtzman, K., & Bucak, S. D. (2008). Retention of basic sciences information by senior medical students. *Academic Medicine, 83,* S82–S85.

Lydeard, S. (1996). Avoid surveys masquerading as research [commentary]. *British Medical Journal, 313,* 733–734.

McAvoy, B. R., Kaner, E. F. S. (1996). General practice postal surveys: a questionnaire too far? *British Medical Journal, 313,* 732–733.

McGuire, A. L., Diaz, C. M., Wang, T., & Hilsenbeck, S. G. (2009). Social networkers' attitudes toward direct-to-consumer personal genome testing.*The American Journal of Bioethics*, *9*(6-7), 3-10. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/19998099

Miller, F. A., Carroll, J. C., Wilson, B. J., Bytautas, J. P., Allanson, J., Cappelli, M., et al. (2010). The primary care physician role in cancer genetics; a qualitative study of patient experience. *Family Practice, 27,* 563–569.

Morren, M., Rijken, M., Baanders, A. N., & Bensing, J. (2007). Perceived genetic knowledge, attitudes towards genetic testing, and the relationship between these among patients with a chronic disease. *Patient Education and Counseling, 65*(2), 197–204.

Mountcastle-Shah, E., & Holtzman, N. A. (2000). Primary care physicians' perceptions of barriers to genetic testing and their willingness to participate in research. *American Journal of Medical Genetics, 94*(5), 409–416. doi:10.1002/1096-8628(20001023)94:5<409::AID-AJMG13>3.0.CO;2-U [pii].

National Society of Genetic Counselors (2010). *2010 professional status survey: Work environment* retrieved August 8, 2011, from http://www.nsgc.org/MemberCenter/ProfessionalStatusSurveyPSSReports/tabid/253/Default.aspx

North Carolina Medical Society (2011). Retrieved April 12, 2011, from http://www.ncmedsoc.org/

Offit, K. (2008). Genomic profiles for disease risk: predictive or premature? *Journal of the American Medical Association, 299*(11), 1353–1355.

Ohata, T., Tsuchiya, A., Watanabe, M., Sumida, T., & Takada, F. (2009). Physicians' opinion for "new" genetic testing in Japan. *Journal of Human Genetics, 54,* 203–208.

Pathway Genomics (2011). *Pathway genomics terms of service*. Retrieved April 1, 2011, from https://www.pathway.com/about-us/terms-of-service

Pollack, A. (March 19, 2010). *Consumers slow to embrace the age of genomics*. *The New York Times*. Retrieved from http://www.nytimes.com/2010/03/20/business/20consumergene.html?ref=decode-genetics-inc

Powell, K. P., Cogswell, W. A., Christianson, C. A., Dave, G., Verma, A., & Henrich, V. C. (2011). Primary care physicians awareness. Experience and Opinions about Direct-to-Consumer Genetic Testing. *Journal of Genetic Counseling*. doi:10.1007/s10897-011-9390-9.

Reigert-Johnson, D. L., Korf, B. R., Alford, R. L., Broder, M. I., Keats, B. J. B., Ormond, K. E., et al. (2004). Outline of a medical genetics curriculum for internal medicine residency training programs. *Genetics in Medicine, 6,* 543–547.

Report, V. I. (2005). *Contemporary issues in medicine: Genetics education*. Washington DC: Association of American Medical Colleges.

Scheuner, M. T., Sieverding, P., & Shekell, P. G. (2008). Delivery of genomic medicine for common chronic adult diseases. *Journal of the American Medical Association, 299,* 1320–1334.

Suther, S., & Goodson, P. (2003). Barriers to the provision of genetic services by primary care physicians: a systematic review of the literature.*Genetics in Medicine, 5,* 70–76.

Swanson, D., Case, S., Leucht, R., & Dillon, G. (1996). Retention of basic science information by fourth-year medical students. *Academic Medicine, 71,* S80–S82.

Thurston, V., Wales, P., Bell, M., Torbeck, L., & Brokaw, J. (2007). The current status of medical genetics instruction in U.S. and Canadian medical schools. *Academic Medicine, 82*, 441–445.

US Census Bureau (2009). *State median income. Income of households by state: Ranked from highest to lowest using 3-year average (2007–2009).* Retrieved from http://www.census.gov/hhes/www/income/statemedfaminc.html

US Government Accountability Office (July 22, 2010). Direct-To-Consumer genetic tests: Misleading test results are further complicated by deceptive marketing and other questionable practices. *Statement of Gregory Kutz, Managing Director Forensic Audits and Special Investigations*Retrieved August 5, 2011, from http://www.gao.gov/products/GAO-10-847T

Vence, T. (2010). Docs brace for DTC genomics. *Genome Web* Retrieved September 14, 2010, from www.genomeweb.com/print/948602

Watson, E. K., Shickle, D., Qureshi, N., Emery, J., & Austoker, J. (1999). The 'new genetics' and primary care: GPs' views on their role and their educational needs. *Family Practice, 16*(4), 420–425.

Wright, C. F., & Gregory-Jones, S. (2010). Size of the direct-toconsumer genomic testing market. *Genetics in Medicine, 12*(9), 594. doi:10.1097/GIM.0b013e3181ead743.