Supporting Statement A

for

Genomics and Society Public Surveys

REVISED June 27, 2014

Submitted by:
Laura M. Koehly, Ph.D.
Senior Investigator
Social and Behavioral Research Branch
National Human Genome Research Institute
31 Center Dr, Room B1B54
Bethesda, MD 20895
Telephone: 301-451-3999
Fax: 301-480-3108
Email: koehlyl@mail.nih.gov

Table of contents

List of Attachments
(Appearance in Supporting Statement A)

A. Justification

A.1 Circumstances Making the Collection of Information Necessary

This request is for Office of Management and Budget (OMB) approval for the Genomics and Society Public Survey data collection scheduled to begin in 2014 by the National Institutes of Health (NIH), through the National Human Genome Research Institute (NHGRI), in partnership with the Smithsonian Institute. This is a new request.

The National Human Genome Research Institute's (NHGRI), National Institutes of Health (NIH), strategic plan puts a strong focus on understanding more fully the societal implications of recent genomic advances. Currently, there is limited knowledge about the public's view regarding genomics and society. The Smithsonian National Museum of Natural History exhibit, "Genome: Unlocking Life's Code", provides a unique opportunity to obtain the perspective of the public about the behavioral and social issues related to genomics. The collection of information activities set forth herein would be conducted under the authorities granted in the Public Health Service Act, Title 42 USC 285s. Surveys within this Information Collection Request consider a broad range of topics related to Genomics and Society, including the following content areas:

- Beliefs about the role of genomics in health conditions and associated risk factors;
- The role of friends, family, media, and health professionals in gathering and communicating health risk information;

- Implications of genetics knowledge in understanding self-identity, race and ancestry;
- Opinions regarding genetics knowledge necessary for making legal, health, and lifestyle decisions.

The exhibit opened in June, 2013, and will reside at the National Museum of Natural History for fourteen months after which it will travel across the country. Data collection for this project is anticipated to begin in 2014 and continue through the course of the exhibit, including the time in which it will travel to other cities across the country. The planned sample size is approximately 182,500 participants completing at least one of seven available surveys.

This project will help to fulfill the mission of the Institute; specifically, to obtain knowledge about the public's views regarding genomics and society. This information will inform future NHGRI DIR research and community education programs that promote genomic awareness and disease prevention.

A.2 Purpose and Use of the Information Collection

The data to be collected are primarily for research purposes; responses will be summarized and published in scientific journals as well as made available to the public through PubMed Central. Responses may also be used to inform community education programs sponsored by the NHGRI.

Data collection will occur under the direction of the National Institutes of Health (NIH) National Human Genome Research Institute (NHGRI) in partnership with the Smithsonian Institute's National Museum of Natural History. The Smithsonian Institute will be involved in recruitment of participants, as outlined below, but not directly involved in the surveying of participants. Attachment 1 provides a diagram detailing the survey procedures.

Adults (18+ years) will be recruited through the exhibit using three different approaches. First, displays within the exhibit will offer visitors the opportunity to text responses to questions related to genomics and genomic information (see Attachment 2). The display includes the URL and a QR code for the survey website. In addition, respondents will be sent an automatic invitation to complete online surveys and a link to the website containing these surveys. Text message content will be collected by a third party short code texting service that will remove personal identifying information from the text message responses. Text message responses will be displayed on the survey website in word clouds (see, for example, Attachment 3). Second, participants will also be recruited via a link to the surveys on the National Museum of Natural History's exhibit website, unlockinglifescode.org. Third, the URL for this survey site may be advertised separately through media and social media channels. In 2012, 7.6 million people visited the National Museum of Natural History. We estimate that our recruitment efforts will reach 3% of these visitors, 80% of whom will choose to complete one or more of the surveys. If these anticipated recruitment numbers are not met, a market research survey company may be used to recruit participants.

The surveys will be available on a designated survey website hosted by the NHGRI (https://research.nhgri.nih.gov/SocialGenome). Visitors to the survey website can choose to complete one or more of the seven available surveys. After selecting an initial survey to complete, participants will complete an online consent confirming eligibility (see Attachment 4), a short demographic module (see Attachment 5), and the selected survey. Once they complete an initial survey, participants will be offered the option to complete another survey. If they choose to complete more surveys in the same session, they will not be asked to repeat the demographic survey module or consent form. Burden estimates for each survey include completion of the demographic modules and thus, overestimate time to complete when the demographic module is not included. Each survey has separate research aims that address questions important in our understanding of how genomics interfaces with society. These specific aims are detailed below:

Survey: Map Your Social Network

Previous research suggests that families are a social context for which social network-based interventions may be particularly effective in 1) motivating the dissemination of health risk information and 2) engaging families in encouragement and support strategies aimed to facilitate positive adaptation to disease risk (Koehly & Loscalzo, 2009). However, not much is known about other social spheres in which health information is exchanged that may be leveraged in network-based interventions. A large scale collection of social network information from participants from diverse backgrounds will allow for a better understanding of network characteristics associated

with health communication and will be used to identify network typologies that may guide targeted health communication intervention programs. To our knowledge, no such large scale collection of social networks currently exists. The survey items are detailed in Attachment 6; a website screenshot which includes the burden statement, consent, demographic module and survey is provided in Attachment 7.

Survey: Health and Genetics from YOUR Point of View

This survey (see Attachment 8) aims to understand the extent to which people view human characteristics as fixed or malleable, and how such beliefs are related to their perceptions of how risk factors influence their own vs. others' health risks. This research will also capture both cognitive and affective measures of common disease risk perceptions. Ultimately, this research aims to evaluate how risk perception is associated with personality, with the hope of determining whether those relationships shed light on concomitant individual differences in beliefs about the relative impact of risk factors on disease. Attachment 9 contains screenshots of the online survey, including the burden statement, consent, and demographic module.

Survey: Could Your Genes Predict Your Weight?

Genomic risk feedback approaches and personalized prevention strategies with respect to overweight and obesity may, in the future, be successfully developed for widespread use. Some lines of thought and research presuppose that individuals would want to receive such genomic information from their physician and use it in clinically-based lifestyle counseling. However, at present, many patients are resistant to discussing weight with

their physician. The current work assesses whether introducing genomic information about weight and weight management either in its current state of readiness/availability or in its potential future state, will change individuals' attitudes and beliefs about including physicians in weight gain prevention and/or weight management efforts. It also assesses preferences and potential change in preferences for weight management information seeking more broadly. Indeed, if individuals do not want to receive weight-related genomic information from physicians, it will be useful to identify their preferred sources. Attachment 10 contains the items on this survey; Attachment 11 provides screenshots of the survey, including burden statement, consent, and the demographic module.

Survey: Kids, Genes, and Health

It is unknown whether viewing childhood behavioral problems as reflecting either genetic or environmental factors is linked to adult decisions about whether to seek help for such problems from health care professionals. A focus on parental understanding of childhood behavioral disorders is timely given that the tool used to define psychiatric disorders, the Diagnostic and Statistical Manual of Mental Disorders, is undergoing a major revision. This revision was partly driven by epidemiological studies suggesting that childhood behavioral disorders are not categorical, but rather represent the extremes of distributions of behavioral traits that span the childhood population, and will incorporate this concept of dimensionality of behaviors in the diagnostic criteria. A key question is whether parents might exhibit different treatment behaviors when the same behavioral problems are explained or presented to them as a ‘disorder’ (the traditional categorical

model) or as representing the extremes of a behavioral distribution. We thus aim to 1) test for associations between adult's attributions of childhood behavioral problems and the tendency to seek help for the child and its exact form and 2) determine if the presentation of the same behavioral problem in dimensional rather than categorical terms is associated with different treatment seeking proclivities. We will randomize respondents to one of two surveys that vary scenarios presented to respondents. The surveys are provided in Attachment 12, and screenshots with the burden statement, demographic module, and surveys in Attachment 13.

Survey: Celebrities, Prescription Drugs & Salmon

Consumers are now encountering a number of new applications of genomics in their daily life. Currently, there are numerous examples of mass media advertisements of new products that make claims about how emerging genetic science has been used to improve the product (e.g., cosmetics, health enhancements and food products (i.e. salmon)). Additionally, genomic discovery increasingly is being integrated into forensic science and used as evidence in criminal investigations. Thus, individuals may be called upon to consider such information in public service roles (e.g. jury duty). Considerable concern has been raised that the public does not have adequate levels of genetic literacy, that is, the ability to accurately understand and use genetic information to make informed decisions about these products and activities. However, it also is unclear what consumers would need to understand to be well-informed. The aim of this survey (see Attachment 14) is to have participants consider scenarios in which they might encounter genomic-based products and in turn which facts would be most useful to

know in these scenarios. The scenarios will be presented in random order to participants. Key to this endeavor is to reach a broad and demographically heterogeneous sample of consumers. Attachment 15 contains the screenshots for this survey, including the burden statement and demographic module.

Survey: Will Genome Sequence Information Change How You View Yourself?

The promise of genome sequencing to enhance understanding of the genetic origin of disease and disease risk, and improve treatments suggests it will have a substantial positive effect on people's health. However, if the information is viewed as indicating something fundamentally negative about who we are, such perceptions may impede uptake of health treatment and prevention behaviors. Understanding whether learning results from genome sequencing may have an impact on self-concept will facilitate design of downstream studies of interventions aimed at mitigating more negative self-views. In this survey (see Attachment 16), we aim to explore the impact of (hypothetical) results from genome sequencing on individuals' self-concept. More specifically, if one were to receive a result from genome sequencing that predicted a future disease risk, would one alter his/her self-concept to that of a less healthy or more vulnerable person? Similarly, if one were to receive a result from genome sequencing that indicated new information about one's ancestry, would one alter his/her self-concept? Our interest in simultaneously studying the effect on self-concept of learning new information about one's ancestry provides a contrast to genomic health information to assess whether any threat to self-concept is uniquely health

related. Respondents will be randomized to one of the two proposed scenarios (genome sequencing results or ancestry results). Our survey also includes validated scales on contingencies of self-worth and clarity of self-concept to assist in interpreting the data on genome sequencing and self-concept. Attachment 17 includes screenshots of the burden statement for this survey, the demographic module and the survey items.

Survey: Exploring Our Identity: Genetics, Ancestry, and Race

In recognition of the emerging genomic research related to assessing the complex relationships among self-identified race, ancestral origin and genetic components of diseases, it is important to study the public's opinions of race, ancestry and identity. The aim of this study is to investigate how the public understands genomics, race, identity, and ancestry and how these concepts interact with disease risk. Attachment 18 details the items on this survey; Attachment 19 includes the screenshots for this survey.

A.3 Use of Information Technology and Burden Reduction

Participants will primarily be recruited within the exhibit. Specifically, displays within the exhibit will offer visitors the opportunity to text responses to questions related to genomics, genomic information and the intersection of genomics with society. Respondents will be sent an automatic invitation to complete online surveys and a link to the website containing these surveys. Text message content will be collected by a third party short code texting service, which will remove personal identifying information from the text message responses. The texting service's Privacy Policy is detailed in Attachment 20, and has been approved by the NHGRI

IT Privacy Liaison. This recruitment approach reduces the burden to the NHGRI research staff.

The surveys will be available on a designated survey website hosted by the NHGRI Division of Intramural Research (DIR) Bioinformatics Core on research.nhgri.nih.gov (URL: research.nhgri.nih.gov/SocialGenome) and stored on a secure NHGRI server. Both the survey website and the database storage system have received Certification within NCAT. The Privacy Impact Assessment (PIA) for the Genomics and Society Surveys was submitted to the NIH Senior Official for Privacy (See Attachment 21)

The information will be collected through an online survey. The use of an online survey reduces the burden to participants, as they can complete the surveys when and where it is convenient for them, and will not have to travel to an assessment site. The burden is also reduced for the NHGRI research staff since assessments will not be conducted in person and data is automatically saved in a secure database.

Upon visiting the website, participants will be given background information on the research, including the expected time burden for survey completion, and will have a list of surveys from which to choose. They are not required to complete any surveys, and may choose to complete one or more surveys. After selecting a survey, they will read a consent form, confirm that they are 18 years or older, and select “accept” if they consent and would like to continue. Next they will fill out a demographic module and start the survey. Upon completion of a survey, participants will be given the option to complete another survey from the list or to leave the site. If the participant

completes another survey in the same session, he/she will not need to fill out the demographic form or consent form again in order to eliminate unnecessary burden. Responses will be chained within a given survey session. However, if the participant chooses to come back to the website to complete further surveys at another time, they will have to re-consent and complete the demographic survey module again, since no identifying information will be stored from participants.

Participants will be informed that their participation is completely voluntary, that they will be able to stop their participation in this project at any point during the study or skip any questions that they feel uncomfortable answering. Additionally, participants will be informed that no personally identifiable information (PII) will be stored and all responses will be protected and secured to the extent permitted by law. This project has been approved, following exempt review, by the NIH Office of Human Subjects Research and the Smithsonian Institutes' Institutional Review Board (see Attachment 22).

A.4 Efforts to Identify Duplication and Use of Similar Information

Significant efforts have been made to minimize duplication of similar information. There are few studies that have examined the intersection of genomics and society, with no examples in the literature that have considered the research aims proposed in this application. Below, a brief summary of these efforts are detailed.

Survey: Map Your Social Network

There is evidence that the structure of support exchange among family members is associated with both emotional and behavioral adaptation to genetic/genomic disease risk (Koehly et al., 2008; Ersig, Williams, Hadley, & Koehly, 2009; Koehly & Hadley, 2008). However, not all relationships within family systems are supportive in nature. Previous findings from the hereditary cancer literature suggest that family conflict is a barrier to risk dissemination (Koehly et al., 2003). Few studies have examined the role of non-supportive relationships in family-level approaches to adaptation. Additionally, there is limited knowledge as to the role that non-biological network members may play in the dissemination of health information and support processes. The current project will fill this gap in the literature by evaluating how non-supportive relationships (e.g. conflict, control, and lack of support) are associated with the adaptation process and the role of non-biological network members in risk communication and adaptation.

Survey: Health and Genetics from YOUR Point of View

Most work on perceptions of malleability has focused on non-health characteristics and outcomes, necessitating a closer look at beliefs in the health domain. Moreover, very little work assesses risk perceptions related to genetic risk in multiple ways, nor examines associations between those measures and beliefs about risk factors. This is essential work in order to best understand how people think about genetic risk vis-à-vis other risks.

Survey: Could Genes Predict Your Weight?

There are no studies in the literature that address the research questions posed in this survey. There is a small body of research that addresses patient preferences for weight management counseling in collaboration with primary care physicians. There is also a small literature assessing public reactions to receipt of obesity-related genomic information. However, these two areas have never before been brought together. This will be necessary to prepare for integration of weight-related genomics information into clinical care.

Survey: Kids, Genes, and Health

There is a dearth of empirical research on how adult's attributions of a child's behavioral problems impact seeking help for the child. A wide range of attributions for one of the most common disorders of childhood-Attention Deficit Hyperactivity Disorder– has been reported, ranging from life events, to genetic factors and birth trauma (Bussing et al., 2006). However, it is unknown whether these different attributions impact on whether a parent decides to seek help for a child, and from whom.

Survey: Celebrities, Prescription Drugs & Salmon

Our research group has conducted several literature reviews over the last five years regarding genetic literacy. The primary focus of this literature has been to document that the public has poor understanding of the basic biology of genetics. These findings then have been interpreted to suggest broad based public education efforts. To date there has been no related research to evaluate public education regarding genetics. This may be due in part to the lack of understanding of what the public needs to know. Thus, the

participants in this study are unlikely to have completed any surveys similar to what is being proposed.

Survey: Will Genome Sequence Information Change How You View Yourself?

The formative literature on self-concept appeared in the 1970's. Since that time the definition has been refined, scales have been developed and the concept has been studied extensively in social psychology. In the mid-1980's, the dynamic nature of self-concept was proposed and studies have subsequently focused on the phases and contextual circumstances associated with multiple notions of oneself. Scholarship exists on self-concept and academic success, leadership, and other life achievements. In the health literature, it has been used as an outcome measure for intervention trials, although studies on the affect of health risk on self-concept are lacking. In a novel 2009 study, Esplen and colleagues assessed changes in self-concept following receipt of a *BRCA1/2* test result (Esplen et al., 2009). This study is the sole example of exploring the effect of genetic test results on self-concept. No studies have assessed the effects of genome sequencing information on self-concept.

Survey: Exploring Our Identity: Genetics, Ancestry, and Race

A comparable study has not been conducted with the public. A literature review has not identified a similar survey or study of this design.

A.5 Impact on Small Businesses or Other Small Entities

No small businesses will be involved in this study.

A.6 Consequences of Collecting the Information Less Frequently

This is a single time research study, although the respondents can choose to respond to multiple surveys provided on the study website.
Since no personal identifying information will be saved from study participants, it is possible that a participant may choose to complete the same survey multiple times.

A.7 Special Circumstances Relating to the Guidelines of 5 CFR 1320.5

The project fully complies with all guidelines of 5 CFR 1320.5.

A.8 Comments in Response to the Federal Register Notice and Efforts to Consult Outside Agency

The proposed information collection was published in the Federal_Register on April 25, 2013, pages 24427-24428 and allowed 60-days for public comment. No public comments were received.

Individuals from within the NHGRI, the broader NIH scientific community, the Smithsonian Institute, and numerous outside companies were consulted from October 2012 to the present, and these consultations are ongoing. The individuals consulted include designers of the exhibit, experts in information technology, and scientific experts in the content domains considered within the surveys. During these consultations, all issues raised were satisfactorily resolved. Development of the surveys and web-based survey infrastructure

for this request for information collection was conducted by scientific and bioinformatics experts at the NIH, with the NHGRI leading the effort.

A.9 Explanation of Any Payment of Gift to Respondents

No payments are to be offered in regard to this information collection. Participants completing the "Map your Social Network" survey will be able to capture and print a copy of their personal social network. They may choose to post this graphic to their personal social media website (i.e. Facebook, Twitter, Pinterest). Once they leave the survey website, they will not be able to recapture their data, since no personally identifiable information, including names of network members and social media identifying information, will be stored in the study database.

A.10 Assurance of Confidentiality Provided to Respondents

No personally identifiable information will be retained in the study database. The cell phone numbers of participants who respond to the exhibit text questions will be removed from their responses by a third party short code texting company. Before completing any survey, participants will be provided with an online consent form explaining the measures taken to maintain their anonymity. Upon consent to complete a study survey, responses will be assigned a random number; this random number will be used to link responses completed by the participant within the same session.

A.11 Justification for Sensitive Questions

No personally identifiable information is being retained in the study database. Participants will provide online consent before completing the study.

A.12 Estimates of Hour Burden Including Annualized Hourly Costs

Average hour burden for the Genomics and Society Surveys is presented in Table 1. The annualized cost to respondents associated with the completion of each survey is presented in Table 2. Burden estimates are based on the informal pre-testing of each instrument with fewer than 9 individuals. The estimate for hourly wage of respondents is based on the national median hourly estimate for all occupations reported in the Bureau of Labor Statistics' Occupational Employment Statistics, May 2013 National Occupational Employment and Wage Estimates United States (http://www.bls.gov/oes/2013/may/oes_nat.htm).

Table 1. Genomics and Society Surveys hour burden estimates

Survey Name	Number of Respondents	Number of Responses Per Respondent	Average Burden Hours Per Response	Total Annual Burden Hours Requested
Text Responses	228,000	5	1/60	19,000
Survey: Map Your Social Network	30,000	1	35/60	17,500
Survey: Health and Genetics from YOUR Point of View	30,000	1	25/60	12,500
Survey: Could Your Genes Predict Your Weight?	30,000	1	20/60	10,000
Survey: Kids, Genes, and Health	30,000	1	17/60	8,500
Survey: Celebrities, Prescription Drugs & Salmon	30,000	1	20/60	10,000
Survey: Will Genome Sequence Information Change How You View Yourself?	30,000	1	10/60	5,000
Survey: Exploring Our Identity: Genetics, Ancestry, and Race	30,000	1	20/60	10,000
Totals				92,500

Table 2. Genomics and Society Surveys annualized cost to respondents.

Survey Name	Number of Respondents	Number of Responses Per Respondent	Average Burden Hours Per Response	Hourly Wage Rate	Respondent Cost
Text Responses	228,000	5	1/60	$16.87	$320,530
Survey: Map Your Social Network	30,000	1	35/60	$16.87	$295,225
Survey: Health and Genetics from YOUR Point of View	30,000	1	25/60	$16.87	$210,875
Survey: Could Your Genes Predict Your Weight?	30,000	1	20/60	$16.87	$168,700
Survey: Kids, Genes, and Health	30,000	1	17/60	$16.87	$143,395
Survey: Celebrities, Prescription Drugs & Salmon	30,000	1	20/60	$16.87	$168,700
Survey: Will Genome Sequence Information Change How You View Yourself?	30,000	1	10/60	$16.87	$84,350
Survey: Exploring Our Identity: Genetics, Ancestry, and Race	30,000	1	20/60	$16.87	$168,700

Totals	$1,560,475

A.13 Estimate of Other Total Annual Cost Burden to Respondents or Record Keepers

There are no capital costs associated with this collection.

A.14 Annualized Cost to the Federal Government

The estimated annualized cost to the Federal Government to support this information collection is $195,788. This estimate is based 5% effort from 11 FTEs of federal staff responsible for the administrative and scientific aspect of the proposed work, one programmer developing and maintaining the survey website, as well the equivalent of one full-time postdoctoral fellow involved in the dissemination of research findings. Table 3 provides the personnel costs for this request, totaling $135,788. Title 42 pay bands can be found at: https://intrahr.od.nih.gov/executive/title42/documents/2010PayRanges.pdf; the General Schedule salaries can be found at: http://www.opm.gov/policy-data-oversight/pay-leave/salaries-wages/2014/general-schedule/; and the fellow stipends can be found at: http://oma1.od.nih.gov/Manualchapters/person/2300-320-7/Appendices/PostBacc14.PDF. This annualized cost estimate also includes estimates for operational expenses (including equipment, overhead, and printing) that would not be incurred without this collection of information at $5,000 per annum. In addition, this cost estimate includes $55,000 per annum allocated to the third party texting contract and the use of a market research survey

company to improve recruitment efforts if necessary. This cost estimate considers conducting information collection activities, including the design and development of the surveys, survey website, data collection, editing, coding, tabulation, data analysis, and the reporting and dissemination of results.

Table 3. Government Personnel Costs

Personnel	% Effort	Salary	Total Personnel Cost
FTE			
NHGRI – Senior Investigator Title 42	5	$216,320	10,816
NHGRI – Senior Investigator Title 42	5	$164,300	8,215
NCI - Senior Program Leader Title 42,	5	$200,000	10,000
NHGRI – Investigator Title 42	5	$167,500	8,381
NHGRI – Staff Scientist Title 42	5	$150,615	7,531
NHGRI – Staff Scientist Title 42	5	$200,000	10,000
NHGRI – Staff Scientist Title 42	5	$119,746	5,987
NHGRI – Staff Scientist Title 42	5	$107,170	5,359
NHGRI – Staff Scientist Title 42		$111,100	5,555
NHGRI – Geneticist GS 12, Step 8	5	$93,264	4,663
NHGRI –Management Analyst GS 13, Step 7	5	$107,909	5,396
Contractor			
NHGRI – Information Technology Expert Contractor	5	$137,696	6,885
Fellow			
NHGRI – Postdoctoral Fellow IRTA Fellow	100	$47,000	$47,000
Grand Total			$135,788

A.15 Explanation for Program Changes or Adjustments

This is a new collection of information.

A.16 Plans for Tabulation and Publication and Project Time Schedule

The data to be collected are primarily for research purposes; thus, responses will be summarized and published in scientific journals and made available to the public through PubMed Central. Table 4 details the timeline for project related activities. Data Analysis and Publication are projected to begin 24 months after OMB approval. The specific analytical plans for each survey are detailed below.

Table 4. Estimated Project Time Schedule

Activity	Time Schedule
Survey	1 - 36 months after OMB approval
Analyses	6 months after completion of survey collection
Publication	6 months after completion of analysis

Survey: Map Your Social Network

Two primary aims will be considered within this research. The first will describe the networks in terms of composition, function and structure (CFS) and identify network typologies characterized by varying CFS. Standard network descriptive statistics, quadratic assignment and clustering procedures and graphical approaches will be used to describe the CFS and

identify network typologies. The second will consider positive and negative social pathways that underlie health risk communication and well-being. Analyses considering relational outcomes, such as health communication, will use graphical modeling techniques. Individual-level outcomes, such as well-being, will be analyzed using linear and non-linear regression techniques.

Survey: Health and Genetics from YOUR Point of View

The primary aim of this work is to evaluate the association between cognitive and affective measures of perceived risk with measures of self-concept and beliefs about the impact of risk factors on health. Specifically, a mediational model will be fitted using regression techniques testing whether self-concept mediates the association between perceived risk and beliefs about the relative impact of disease-relevant risk factors.

Survey: Could Your Genes Predict Your Weight?

Descriptive statistics will be used to identify where participants actively seek information regarding factors that influence weight, who they talk to about weight related concerns, including health care providers, and beliefs about the causes of weight, including genes. Using repeated measures ANCOVA, shifts in attitudes and beliefs about including their health care providers in weight gain prevention and /or weight management efforts across three different scenarios regarding the application of genetics and genomics for weight management will be explored. Further, differences across these scenarios in preferences for acquiring weight-related information more broadly will be examined using generalized linear models.

Survey: Kids, Genes, and Health

This research has two primary hypotheses that will be explored. The first investigates whether adults who hold a genetic attribution for childhood behavioral problems will be more likely to view medical interventions as appropriate. Correlational analyses will be performed to examine the association between an aggregate measure of genetic attributions to childhood behaviors and perceptions that medication and/or therapeutic treatments are appropriate for the behavior, controlling for covariates such as having a child affected by a behavioral disorder (e.g. ADHD or Autism). The second investigates whether descriptions of behavioral problems in dimensional rather than categorical terms will be associated with a decreased likelihood to view medical interventions as appropriate. Respondents will be randomly assigned one of two different forms of the survey, one in which descriptions of behavioral problems are in categorical terms and the other in dimensional terms. Differences in opinions regarding medical interventions across the two forms will be assessed using generalized linear modeling approaches.

Survey: Celebrities, Prescription Drugs & Salmon

Items will be aggregated within scales and descriptive statistics computed to describe participants genetic literacy, numeracy, importance of learning genetics, and confidence with applying genetics in public service or consumer roles. Correlational analyses will evaluate associations between genetic literacy, numeracy and confidence. Using repeated measures ANCOVA, differences in participants' confidence in applying genetics knowledge to problems detailed in five scenarios participants might encounter in their daily lives will be assessed.

Survey: Will Genome Sequence Information Change How You View Yourself?

Factor analytic approaches will be used to evaluate the construct validity for items assessing contingencies of self-worth, self-concept, and clarity of self-concept. Structural equation modeling will be used to examine the relationships between self-worth, self-concept, and clarity of self-concept, and whether those relationships differ across the two scenarios presented in the surveys. Specifically, these two scenarios consider whether genome sequencing reveals new information regarding disease risk or ancestry.

Survey: Exploring Our Identity: Genetics, Ancestry, and Race

Descriptive statistics will be computed to assess the public's views regarding genetic ancestry testing, attitudes and beliefs about race and biological definitions of race, and the use of ancestry information in health care decision and other social contexts, such as law enforcement and college admissions. Correlational analyses will examine associations between self-identified race and ethnicity and attitudes and beliefs about the genetic basis of race and the use of genetic ancestry in decision-making.

A.17 Reason(s) Display of OMB Expiration Date is Inappropriate

Not Applicable

References

Bussing, R., E Koro-Ljungberg, M., Williamson, P., Gary, F. A., & Wilson Carvan, C. (2006). What "dr. mom" ordered: a community-based exploratory study of parental self-care responses to children's ADHD symptoms. *Social Science & Medicine, 63*, 871-82.

Ersig, A. L., Williams, J. K., Hadley, D. W., Koehly, L. M. (2009). Communication, encouragement, and cancer screening in families with and without mutations for hereditary nonpolyposis colorectal cancer: a pilot study. *Genetics in Medicine, 11*, 728-34.

Esplen, M. J., Stuckless, N., Hunter, J., Liede, A., Metcalfe, K. … Irwin, E. (2009). The BRCA self-concept scale: a new instrument to measure self-concept in BRCA 1/2 mutation carriers. *Psychooncology, 11*, 1216-29.

Koehly L. & Hadley D. (2008). Encouragement to screen in families affected by Lynch syndrome. *Paper presented in the symposium entitled Family-based Approaches to Understanding and Intervening in Cancer Screening at the annual meeting of the Society of Behavioral Medicine.* San Diego, CA.

Koehly, L.M., Peters J., Kuhn N., Hoskins, L., Letocha, A., … Greene, M. H. (2008). Sisters in hereditary breast and ovarian cancer families: communal coping, social integration, and psychological well-being. *Psycho-Oncology, 17*, 812-821.

Koehly, L.M., Peterson, S.K., Watts, B. G., Kempf, K. K. G., Vernon, S. W., Gritz, E. R. (2003) A social network analysis of communication about hereditary nonpolyposis colorectal cancer genetic testing and family functioning. *Cancer Epidemiology Biomarkers & Prevention, 12*, 304-313.