Supporting Statement B

for

Genomics and Society Public Surveys

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B. Collections of Information Employing Statistical Methods

B.1 Respondent Universe and Sampling Methods

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. Data collection for this project is anticipated to begin early 2014 and continue through the course of the exhibit, including the time in which it will travel to other cities across the country. 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, texters will be sent an automatic invitation to complete online surveys and a link to the website containing these surveys. Text message responses will be displayed on the survey website in word clouds in an effort to attract potential participants to the survey website (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.

It is anticipated that visitors to the exhibit or supporting websites will be of various cultural backgrounds and of different ages and gender. Inclusion criteria include being aged 18 years or older, ability to complete a web-based survey, and the ability to read English. The sample will represent a convenience sample based on the number of visitors to the museum or supporting websites. Based on a recent Smithsonian Institutes – Natural History Visitorship Study (conducted over 2010-2011), 80% of visitors were non-Hispanic white, 10% Hispanic, 8% African American, and 7% Asian American; 86% were US Citizens and 14% foreign nationals. Gender balance was equal and average visitor age was 37 years. The majority of visitors (72%) reported at least completion of BA level education. We anticipate our sample will look similar to this group. In 2012, 7.6 million people visited the National Museum of Natural History. If we condition on this population, 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. The planned sample size is approximately 182,500 participants completing at least one of seven available surveys. If these anticipated recruitment numbers are not met, a market research survey company may be used to recruit participants.

Table 1. Genomics and Society Surveys: Universe of potential participants and expected number of respondents.

Population	**Universe of Potential Participants**	
National Museum of Natural History Visitors	7.6 Million	
Survey Name	**Number of Respondents**	**Estimated Response Rate**
Text Responses (Number of Visitors Reached)	228,000	
Total Survey Responders	182,500	80%
Individual Surveys	**Number of Respondents**	
Survey: Map Your Social Network	30,000	
Survey: Health and Genetics from YOUR Point of View	30,000	
Survey: Could Your Genes Predict Your Weight?	30,000	
Survey: Kids, Genes, and Health	30,000	
Survey: Celebrities, Prescription Drugs & Salmon	30,000	
Survey: Will Genome	30,000	

Sequence Information Change How You View Yourself?	
Survey: Exploring Our Identity: Genetics, Ancestry, and Race	30,000

B.2 Procedures for the Collection of Information

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, those replying to the exhibit text questions will be sent an automatic invitation to complete online surveys and a link to the website containing these surveys. Text message responses will be displayed on the survey website in word clouds in an effort to attract potential participants to the survey website (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.

There will be no oversampling, stratified sampling, or random sampling methodologies used. The resulting sample is based on a convenience sample obtained through the exhibit, supporting websites, or

other media and social media channels. If anticipated recruitment numbers are not met, a market research survey company may be used to recruit participants. In this context, eligible participants will be used based on random sampling from such companies' bank of potential participants.

The proposed data collection is a single data collection. There will be no follow up data collection. Thus, the burden of multiple data collection points is not relevant for this request. 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.

Additionally, upon selecting a survey on the website to complete, participants will fill out a demographic module before they 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 since responses will be chained within a given survey session.

B.3 Methods to Maximize Response Rates and Deal with Nonresponse

Given that this is a series of public surveys related to genetics and genomics, recruitment of participants through the Smithsonian's Unlocking Life's Code exhibit is aimed at maximizing response rates for those interested in the role of genetics and genomics in society. The estimated response rate for

the set of surveys is based on the number of survey responders completing the demographic module (numerator) divided by the number of unique texters (denominator). If a market survey research firm is also used to recruit participants, the denominator will be adjusted accordingly. While it is possible to reach potential participants by other means (traditional and social media outlets, word of mouth), it may be infeasible to adjust the denominator for the response rate to include those reached outside of the text messaging component of the exhibit or those recruited through the market research firm, though good faith efforts will be made to do so where possible. Thus, the estimated response rate may overestimate the actual response rate. Additionally, the response rate for completing a given survey relative to the other surveys in the assessment will be computed using the number of participants completing the survey in question (numerator) compared to the number of participants completing the demographic module (denominator). The demographic module will be presented at the front of the first survey that a given respondent completes. Thus, characteristics of completers and non-completers can be described and differences in respondent characteristics across surveys can be ascertained.

Estimated response rates, based on the pool of potential participants reached through the exhibit text questions, supporting websites, and market research firms, are 80%. While this estimate is larger than that observed in other internet based assessments (cf Zhang, 2000; Kaplowitz, Hadlock, and Levine, 2004), we propose that using this innovative multi-pronged recruitment approach that targets potential participants through the exhibit text messaging, QR codes, supporting websites, media and social media

outlets, and survey marketing companies will maximize the expected response rate.

Most of the surveys contain psychometrically sound scales, based on the literature (Campbell, et al., 1996; Crocker, et al., 2003; Crocker and Wolfe, 2001; Dweck, Chiu, and Hong, 1995; Esplen, et al., 2009; Fagerlin, et al., 2007; Fitz, Kaufman, and Moore, in press; Han, Moser, and Klein, 2006; Heatherton, et al, 1989; Hooker, et al., in press; Koehly, et al., 2003; Marcum, Hadley, and Koehly, 2014; McBride, Wade, and Kaphingst, 2010; Shepperd, Helweg-Larsen, and Ortega, 2003; Utsey and Constantine, 2006; Weinstein, et al., 2007; Yong, et al, 2013; Vieter, 2001). Additionally, many items came from national surveys, including NHANES and HINTS. As such, these should yield reliable and valid data points for the proposed data 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. In scientific publications, the sampling approach, response rates, and characteristics of responders, non-responders will be fully described in order to best represent the characteristics of the sample. Additionally, the Smithsonian Institutes has basic demographic information about their visitors that can be used to assess how the obtained sample differs from the universe of adult museum visitors.

B.4 Test of Procedures or Methods to be Undertaken

The online surveys were pre-tested by at most 5 respondents per survey with varying levels of educational attainment, race/ethnicity, and gender. Revisions were made to the survey to facilitate understanding, ease of use, and to estimate the time burden for each survey. These revisions were made to the surveys prior to submission of this application.

B.5 Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data

The following individuals have been consulted on statistical aspects of the design, development of the survey website, and/or will analyze the obtained data.

Website Development

David Kanney, Contractor, NHGRI	301-435-6076

Survey Design and Analysis

Barbara Biesecker, PhD, Associate Investigator, NHGRI	301-496-3979
Rebecca Ferrer, PhD, Health Scientist, NCI	240-276-6824
Annette Kaufman, PhD, Health Scientist, NCI	240-276-6824
William Klein, PhD, Associate Director, Behavioral Research, NCI	240-276-6824
Laura Koehly, PhD, Senior Investigator, NHGRI	301-451-3999
Christopher Marcum, PhD, Staff Scientist, NHGRI	301-594-6240
Colleen McBride, PhD, Senior Investigator, NHGRI	301-594-6788

Heather Patrick, PhD, Health Scientist, NCI	240-276-6824
Susan Persky, PhD, Associate Investigator, NHGRI	301-443-0098
Philip Shaw, PhD, Investigator, NHGRI	301-451-4010
Jennifer Tabor, PhD, CRTA Fellow, NCI	240-276-6824

Data Management and Analysis

The Social and Behavioral Research Branch (SBRB), NHGRI, has a longstanding contract (9 years) with Abt Associates to serve as the branch's "statistical core". This core provides an array of statistical support services conducted by a cadre of skilled (mostly master's trained) statisticians. The statisticians who are assigned to data analysis tasks vary depending on the analyses to be conducted. As a paid service provider, the statisticians are not co-authors on manuscripts or co-investigators. Instead, these statisticians follow the direction of study investigators in conducting univariate, bivariate, and multivariate analyses of data provided to them by SBRB investigators. The SBRB investigators (named in this request) are responsible for directing and interpreting the analyses. Abt services (including data file creation) and analysis is described and reviewed in our Human Subjects Research proposals and subject to the requirements of confidentiality (e.g., secure data transfer, and protections of confidential

data). The project director is Dr. Chanza Baytop who is a Senior Associate| Abt Associates (O: 301-634-1727 | M: 443-506-8984 | F: 301-828-9756 | www.abtassociates.com). Dr. Baytop will not serve as a co-investigator or data analyst but oversees the assignment of statisticians to projects. All of the 7 projects in this protocol will be eligible to receive services provided by the Abt statistical core.

References

Campbell, J.D., Trapnell, P.D., Heine, S.J., Katz, I.M., Lavallee, L.F., & Lehman, D.R. (1996). Self-concept clarity: Measurement, personality correlates, and cultural boundaries. *Journal of Personality and Social Psychology, 70*(1),141-156.

Crocker, J., Luhtanen, R.K., Cooper, M.L., & Bouvrette, A. (2003). Contingencies of self-worth in college students: theory and measurement, *Journal of Personality and Social Psychology, 85*(5), 894-908.

Crocker, J. & Wolfe, C.T. (2001). Contingencies of self-worth *Psychological Review, 108*(3), 593-623.

Dweck, C. S., Chiu, C., & Hong, Y. (1995). Implicit theories and their role in judgments and reactions: A world from two perspectives. *Psychological Inquiry*, 6(4), 267-285

Esplen, M.J., Stuckless, N., Hunter, J., Liede, A., Metcalfe, K., Glendon, G., Narod, S., Butler, K., Scott, J., & Irwin, E.. (2009). The *BRCA* Self-Concept Scale: a new instrument to measure self-concept in *BRCA1/2* mutation carriers. *Psychooncology*, *18*(11), 1216-29.

Fagerlin, A., Zikmund-Fisher, B.J., Ubel, P.A., Jankovic, A., Derry, H.A., & Smith, D.M. (2007). Measuring numeracy without a math test: Development of the Subjective Numeracy Scale. *Medical Decision Making*, *27*(5), 672-680.

Han, P.K., Moser, R.P., & Klein, W.M. (2006). Perceived ambiguity about cancer prevention recommendations: Relationship to perceptions of cancer preventability, risk, and worry. *Journal of Health Communication*, *11*(S1), 51-60.

Heatherton TF, Kozlowski LT, Frecker RC, Rickert W, Robinson J. (1989) . Measuring the heaviness of smoking: using self-reported time to the first cigarette of the day and number of cigarettes smoked per day. *British Journal of Addiction*, 84(7), 791-799.

Health Information National Trends Survey (HINTS). Website: http://hints.cancer.gov/

Hooker, G.W, Peay, H., Bayless, T., Biesecker, B. & Roter, D. (*in press*). Testing for Inflammatory Bowel Disease: Genetic Literacy and Appraisals Medical and Genetic Testing Vignettes. *Inflammatory Bowel Disease*.

Kaplowitz, M.D., Hadlock, T.D., & Levine, R. (2004). A comparison of web and mail survey response rates. *Public Opinion Quarterly, 68*(1), 94-101.

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 aboutheredi tary nonpolyposis colorectal cancer genetic testing and familyfunctioning. *Cancer Epidemiology Biomarkers & Prevention, 12*, 304-313.

Marcum, C.S., Hadley, D., & Koehly, L.M. (2014). Multiple-item measurement for relational construct measures. *Paper presented at the annual meeting of the International Network of Social Network Analysis.* St. Petes Beach, FL.

McBride, C.M., Wade, C.H., & Kaphingst, K.A. (2010). Consumers' views of direct-to-consumer genetic information. *Annual Review of Genomics and Human Genetics, 11*, 427-446.

National Health and Nutrition Examination Survey (NHANES). Website: http://www.cdc.gov/nchs/nhanes.htm

Shepperd, J.A., Helweg-Larzen, M., & Ortega L. (2003). Are comparative risk judgments consistent across time and events? *Personality and Social Psychology Bulletin, 29*(9), 1169-1180.

Utsey, S.O. & Constantine, M.G. (2006). A confirmatory test of the underlying factor structure of scores on the collective self-esteem scale in two independent samples of Black Americans. *Journal of Personality Assessment, 86*(2), 172-179.

Vietor NA (2001) Understanding Smoking Relapse from an Implicit Theories Framework. Houston, TX: University of Houston

Weinstein, N.D., Kwitel, A., McCaul, K.D., Magnan, R.E., Gerrard, M., & Gibbons, F.X. (2007). Risk perceptions: Assessment and relationship to influenza vaccination. *Health Psychology*, *26*(2), 146.

Yong, H.H., Borland, R., Balmford, J., Hyland, A., O'Connor, R.J., Thompson, M.E., & Spittal, M.J. (2013). Heaviness of smoking predicts smoking relapse only in the first weeks of a quit attempt: Findings from the International Tobacco Control Four-Country Survey. *Nicotine and Tobacco Research*. ePub ahead of print October 24.

Zhang Y. (2000). Using the Internet for survey research: A case study. *Journal of the Association for Information Science and Technology*, *51*(1): 57-68.