



[BILLING CODE 4140-01-P]

DEPARTMENT OF HEALTH AND HUMAN SERVICES

National Institutes of Health

Proposed Collection; 60-day Comment Request

Genomics and Society Public Surveys in Conjunction with Smithsonian Museum of Natural History Genome Exhibit

SUMMARY: In compliance with the requirement of Section 3506(c)(2)(A) of the Paperwork Reduction Act of 1995, for opportunity for public comment on proposed data collection projects, the National Human Genome Research Institute (NHGRI), National Institutes of Health (NIH), will publish periodic summaries of proposed projects to be submitted to the Office of Management and Budget (OMB) for review and approval.

Written comments and/or suggestions from the public and affected agencies are invited on any of the following points: (1) Whether the proposed collection of information is necessary for the proper performance of the function of the agency, including whether the information will have practical utility; (2) The accuracy of the agency's estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used; (3) Ways to enhance the quality,

utility, and clarity of the information to be collected; and (4) Ways to minimize the burden of the collection of information on those who are to respond, including the use of appropriate automated, electronic, mechanical, or other technological collection techniques or other forms of information technology.

TO SUBMIT COMMENTS AND FOR FURTHER INFORMATION CONTACT: To obtain a copy of the data collection plans and instruments, submit comments in writing, or request more information on the proposed project, contact: Laura M. Koehly, Ph.D., Senior Investigator, Social and Behavioral Research Branch, NHGRI, NIH, 31 Center Drive MSC 2073, Building 31, Room B1B54, Bethesda, MD 20892, or call non-toll-free number (301) 451-3999, or E-mail your request, including your address to: koehlyl@mail.nih.gov. Formal requests for additional plans and instruments must be requested in writing.

COMMENT DUE DATE: Comments regarding this information collection are best assured of having their full effect if received within 60 days of the date of this publication.

PROPOSED COLLECTION: Genomics and Society Public Surveys in Conjunction with National Museum of Natural History Genome Exhibit, 0925-NEW, National Human Genome Research Institute (NHGRI), National Institutes of Health (NIH).

Need and Use of Information Collection: The National Human Genome Research Institute's (NHGRI) 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 upcoming exhibit at the Smithsonian National Museum of Natural History, "Genome: Unlocking Life's Code", provides a unique opportunity to obtain the perspectives of the public about the role of genomics in society. Surveys included in this project 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 race and ancestry;
- Opinions regarding genetics knowledge necessary for making legal, health, and lifestyle decisions.

The exhibit is scheduled to open in June, 2013, and will reside at the National Museum of Natural History for one year after which it will travel across the country. Data collection for this project is anticipated to begin fall, 2013 and continue through the course of the exhibit. 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.

Adults (18+ years) will be recruited through the exhibit using two different approaches. First, interactive displays within the exhibit will offer visitors the opportunity to text responses to questions related to genomics and genomic information. 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. Second, participants will also be recruited via a link to the surveys on the National Museum of Natural History's website. The URL for this survey site may also be advertised separately through media and social media channels.

The surveys will be available on a designated survey website hosted by the NHGRI. Visitors to the survey website can fill out the surveys if they choose. After completing an online consent confirming eligibility and a short demographic module, participants will be offered the option to complete one or more of the seven available surveys. In 2012, 7.6 million people visited the National Museum of Natural History. We estimate that our recruitment efforts will reach 1% of these visitors, 75% 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 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.

OMB approval is requested for 3 years. There are no costs to respondents other than their time. The total estimated annualized burden hours are 32,752.

Estimated Annualized Burden Hours

Form Name	Number of Respondents	Number of Responses Per Respondent	Average Time Per Response (in hours)	Total Annual Burden Hours
Text Responses	76,000	5	1/60	6,333
Consent and Demographics Screener	57,000	1	5/60	4,750
Health Communication and Networks Survey	10,000	1	30/60	5,000
Genomics and Health Beliefs Survey	10,000	1	20/60	3,333
Genomics in Decision Making Survey	10,000	1	15/60	2,500
Genomics of Weight Survey	10,000	1	15/60	2,500
Genomics of Behavioral Dispositions Survey	10,000	1	12/60	2,000
Genomics and Self-Concept Survey	10,000	1	5/60	833
Race, Ancestry, Identity and Genomics Survey	10,000	1	15/60	2,500

Dated: April 19, 2013

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