Supporting Statement A for

**OMB Clearance Request** 

## National Heart, Lung, and Blood Institute

# "Survey of NHLBI Constituents' Health Information Needs and Preferred Formats" (NHLBI, NIH)

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# Contents

A.	Justifi	cation	2
	A.1.	Circumstances Making the Collection of Information Necessary	2
	A.2.	Purpose and Use of the Information Collected	2
	A.3.	Use of Information Technology and Burden Reduction	2
	A.4.	Efforts To Identify Duplication and Use of Similar Information	2
	A.5.	Impact on Small Businesses or Other Small Entities (Burden on Small Businesses)	2
	A.6.	Consequences of Collecting Information Less Frequently (For Periodic Surveys)	2
	A.7.	Special Circumstances Ref. 5 C.F.R. § 1320.5	2
	A.8.	Comments to Federal Register Notice	2
	A.9.	Payments or Gifts to Respondents	2
	A.10.	Assurance of Confidentiality Provided to Respondents	2
	A.11.	Justification for Sensitive Questions	2
	A.12.	Estimates of Hour Burden and Annualized Hourly Costs	2
	A.13.	Other Total Annual Cost Burden to Respondents or Record Keepers	2
	A.14.	Annualized Cost to the Federal Government	2
	A.15.	Explanation of Program Changes or Adjustments	2
	A.16.	Plans for Tabulation and Publication and Project Time Schedule	2
	A.17.	Reason(s) Display of OMB Expiration Date Is Inappropriate	2
	A.18.	Exceptions to Certifications for Paperwork Reduction Act Submissions	2

#### Attachment A. HIC General Survey

Attachment B. Solicitation E-Mails for HIC General Survey

Attachment C. AIR's Security Policies for Hosting External Systems

# A. Justification

#### A.1. Circumstances Making the Collection of Information Necessary

The National Heart, Lung, and Blood Institute (NHLBI), one of the Institutes that constitute the National Institutes of Health (NIH), U.S. Department of Health and Human Services (HHS), provides leadership in the conduct and support of research, training, health information dissemination, and other programs with respect to heart, blood vessel, lung, and blood diseases and sleep disorders. This responsibility is authorized by Congress at 42 U.S.C. § 285b.

The NHLBI's mandate covers three of the four leading causes of death in the United States. As part of its mission, the NHLBI stimulates basic discoveries about the causes of disease, speeds the translation of basic discoveries into clinical practice, fosters training and mentoring of emerging scientists and physicians, and communicates research advances to the public.

The Office of Communications and Legislative Activities (OCLA) provides executive strategic guidance to a dynamic, comprehensive, and technology-supported communications and legislation program for the NHLBI for the purpose of advancing its goals. The OCLA:

- Provides authoritative analysis and advice to the NHLBI Director and executive staff on the formulation of communications and legislative strategies that will be conveyed nationally and abroad.
- Provides a comprehensive, integrated, and technology-supported communications capability for all matters relating to the communication of the Institute's vision, strategic plan, and mission-oriented program activities and accomplishments to internal and external audiences.
- Initiates, develops, and implements a dynamic, proactive, communications program appropriate for intended audiences.
- Involves multiple groups on national and international levels and leverages the communications resources of local, national, and international sources, including audience-specific interest groups.
- Evaluates the effectiveness of communications activities.
- Advises the NHLBI Director, staff, and advisors on the full range of legislative and congressional activities as they relate to the NHLBI mission.
- Coordinates and integrates activities of the Public Affairs Branch, the Health Campaigns and Consumer Services Branch, and the Freedom of Information and Privacy Branch.
- Serves as point of contact for members of Congress, the White House, and HHS responding to inquiries and coordinating preparation of testimony and statements before these groups.
- Reviews, processes, and responds to all requests for information that fall under the jurisdiction of the Freedom of Information Act (FOIA) and Privacy Act.

The OCLA currently produces more than 600 materials in print and electronic formats to educate health professionals and the general public on the diagnosis, treatment, and prevention of the diseases and conditions that fall under its purview. More than 1 million copies of NHLBI print publications have been distributed to the public every year since 2001, with more than 1.9 million print copies distributed in 2008. Downloads of NHLBI information in electronic format and use/reading of health information materials and applications online (such as the Body Mass Index Calculator and the Diseases and Conditions Index, or DCI) disseminate information to millions more in the United States and the rest of the world. A listing of NHLBI educational materials available to the public and health professionals can be found online at <a href="http://www.nhlbi.nih.gov/index.htm">http://www.nhlbi.nih.gov/index.htm</a>.

The OCLA periodically reviews information on NHLBI Health Information Center (HIC) customer orders and Web downloads and assesses which of its current materials and formats are most in demand, and which may not be as important to the public. Customers can rate all NHLBI materials through a product review mechanism on the Institute's Web site. The NHLBI also publishes the customer reviews on its Web site. People also have the option to provide the NHLBI with feedback on DCI articles, and many comments are received and shared with the authors, reviewers, and editors who develop the content for this site. These types of feedback mechanisms provide the OCLA with some important information to help assess its current portfolio of educational materials. Additionally, the OCLA regularly reviews its materials for scientific accuracy and currency and makes revisions as needed to ensure that the information it provides to the public is up to date and authoritative.

Creation of new materials requires a significant investment of NHLBI resources. Every 3 years, the OCLA goes through a comprehensive planning process to create the "NHLBI Strategic Plan for the Development of Education Materials for Health Professionals and the Public" (Strategic Plan). This planning process determines which of the many topics related to heart, lung, and blood diseases will be translated into educational materials, and in what formats, design, and media. The OCLA reviews and updates the Strategic Plan annually. This planning process is particularly important as the variety of materials and formats available to the public for obtaining health information—particularly in electronic form—expands every year. The development of the Strategic Plan is led and coordinated by the OCLA's Consumer Services Team (CST). The CST consists of OCLA staff and is supported by NHLBI HIC contractor staff. Team members have expertise in health communications, health education, materials development, and promotion and marketing of health information.

To support the OCLA's efforts in developing the Strategic Plan, the NHLBI requests clearance for a survey instrument to collect data from NHLBI constituents (health professionals, patients and their families, and the general public) for the purpose of evaluating their health information and education needs and format preferences. The survey is provided in Attachment A.

The NHLBI requests use of this instrument for data collection every 3 years. We will rotate the calendar year quarter for each use of the instrument to help reduce possible seasonal variance bias.

#### A.2. Purpose and Use of the Information Collected

This project will contribute to the OCLA's mission of implementing a dynamic and proactive communications program for health professionals, patients and their families, and the general public to provide effective and accessible health information on diseases of the heart, lungs, and blood vessels and sleep disorders.

The CST will use the data collected in this survey to create a 3-year Strategic Plan for developing new health information materials for NHLBI constituents and revising materials currently in the Institute's portfolio. The survey data will help answer the following questions about the health information materials and services provided by the NHLBI:

- What is the level of interest in information on heart, lung, and blood diseases and sleep disorders?
- What is the level of interest in information on the prevention of cardiovascular disease, heart healthy eating, physical activity, and obesity?
- To what degree are health professionals interested in clinical practice guidelines, Continuing Medical Education (CME), interactive tools for computers, mobile phones and hand-held devices, online health assessment tools, tips for talking to patients, and health information for patients with low reading levels?
- Do NHLBI constituents have health information needs that are not being met with the Institute's current portfolio of materials?
- What is the public's and health professionals' level of interest in health education materials for special population groups?
- How do people use NHLBI information—for example: to find out about their own health or a family member's health, or for professional development, training, or school projects?
- In what formats do NHLBI constituents prefer to receive health information from the NHLBI?
- In addition to the NHLBI, what other resources do constituents use to find health information?
- How do NHLBI constituents hear of the NHLBI HIC?

The data collected with this survey instrument will help the NHLBI make its investment in educational materials development worthwhile as well as cost effective, and to ensure that the public interest is being best served. These data are needed to support NHLBI decision-making on how to invest its limited resources for health information/education materials development. Knowing more about the preferences and needs of its constituents will enable the NHLBI to ensure that the materials it does develop are useful to the public and well received. Ultimately, by developing health information materials under a well-thought-out Strategic Plan, based on key survey data, will increase the chances that NHLBI materials are used by constituents to improve their own health as well as that of others (family members, friends).

The CST will summarize and analyze the data collected with this survey, and use the survey results to develop each 3-year Strategic Plan. The data will provide key information on what

topics, formats, and channels the public needs and prefers. Thus, the survey results will guide the CST in developing the Strategic Plan, ensuring that the health information materials produced by the NHLBI meet the most pressing needs of the public and are accessible, effective, and well received.

The Strategic Plan will be presented by the CST to OCLA management staff for review and approval. The approved Strategic Plan will inform the OCLA's budget development for health information materials development each fiscal year.

In addition, the CST will use the survey data results to evaluate the performance of NHLBI health information materials developed on the basis of the previous survey findings, assess the efficacy of the conclusions drawn from the most recent survey, and identify new data needs for the next survey.

#### Past Data Collections

The NHLBI has not previously undertaken a data collection effort as broad in scope—focused on identifying the unmet health information needs and preferences of its constituents. The NHLBI's previous efforts at data collection on constituent preferences have been anecdotal and very limited in scope. Currently, the OCLA's materials development process is supported by examining recent historical data on customer orders for existing print materials and partial information on downloads of materials in electronic format. Although helpful, this approach is limited in scope and based only on constituent response to materials that the NHLBI has chosen to present to the public.

## A.3. Use of Information Technology and Burden Reduction

We will use a Web-based survey tool (WebSurveyor) residing on a server of the NHLBI HIC contractor (American Institutes for Research, or AIR) to collect data from NHLBI constituents. Previous NHLBI HIC customers (within the past 3 years) will be invited by e-mail to participate in the online survey (see Attachment B for copies of the solicitation e-mails). Constituents who choose to complete the survey will need an Internet connection and a Web browser to access it. The e-mail invitation will include the link to the survey. The survey tool uses skip logic, which will enable respondents to bypass questions that are not relevant to them based on previous answers. This feature will allow respondents to complete the survey in less time.

A Privacy Impact Assessment (PIA) has not been done for the WebSurveyor application to be used for the survey. WebSurveyor will reside on AIR's server behind extensive firewall protection. This version of WebSurveyor is self-hosted rather than outsourced to an external hosting service or accessed through the application's manufacturer's subscription option (see Attachment C, AIR's Security Policies for Hosting External Systems).

# A.4. Efforts To Identify Duplication and Use of Similar Information

The information to be collected from the survey is not available from any other source and does not duplicate any existing data collection effort.

#### A.5. Impact on Small Businesses or Other Small Entities (Burden on Small Businesses)

Individual physician practices are part of the population to be surveyed, and are considered a small business or entity. This collection of information will not unduly impact small organizations or small businesses, therefore no special provisions are necessary for these groups.

The information requested by the survey has been held to a minimum for all respondents, including small businesses. The survey takes an estimated 12 minutes or less to complete, and a shortened version is therefore not necessary for small-business respondents.

## A.6. Consequences of Collecting Information Less Frequently (For Periodic Surveys)

The NHLBI will incur several risks by collecting the data in intervals of more than every 3 years, including:

- In an era of rapid innovation in communications, we will miss opportunities to identify important new channels for disseminating health information to NHLBI constituents, such as texting to mobile phones and other new devices.
- Not meeting public demand for timely access to the most up-to-date scientific and medical information about the prevention, diagnosis, and treatment of diseases of the heart, lungs, and blood vessels and sleep disorders.

# A.7. Special Circumstances Ref. 5 C.F.R. § 1320.5

No special circumstances apply to this study.

## A.8. Comments to Federal Register Notice

The 60-day Federal Register notice of this study was published on March 19, 2009, pages 11736–11737. No requests for information or comments were received.

The NHLBI consulted with experts outside the Institute to obtain their advice on developing the survey tool, data collection method, data evaluation, and other aspects of implementing this survey. These experts are:

- Roger Levine, Ph.D., Managing Research Scientist, American Institutes for Research, 650–843–8160
- Eileen Smith, Marketing Director, American Institutes for Research, 301–592–3330
- Lawrence Thomas, Project Director, American Institutes for Research, 240–629–3232
- Christine Paulsen, Ph.D., Principal Research Scientist, American Institutes for Research, 978–302–5543

Drafts of the survey tool were reviewed by NHLBI OCLA staff and revised to reflect their comments. These staff included Ann Taubenheim, Ph.D., M.S.N. (NHLBI HIC Project Officer), Diane Striar (Acting Branch Chief, Health Communications and Social Marketing), and Gregory Morosco, Ph.D., M.P.H. (former Director, Division for the Application of Research Discoveries).

#### A.9. Payments or Gifts to Respondents

We are not offering payments or incentives to survey respondents beyond the opportunity to receive a summary of the survey results via e-mail after the survey is completed.

#### A.10. Assurance of Confidentiality Provided to Respondents

All survey data will be kept confidential. No personal identifying information will be collected from survey respondents. Survey respondents who request a copy of the results summary will be asked to provide only their e-mail address. These e-mail addresses will be stored in a database on an AIR server and will not be shared with anyone, including staff at the NHLBI. After respondents are sent the results summary, AIR will destroy the e-mail database.

The WebSurveyor tool will assign a unique identifier to each potential respondent in the study tied to his/her e-mail address to ensure one response per respondent. That identifier will not be accessible to anyone but the AIR system administrator for the WebSurveyor tool.

Upon completion of the survey, all data tying the assigned identifier to an e-mail address will be destroyed; namely, the contents of the e-mail fields will be erased.

The database for the survey will be located on the AIR servers behind extensive firewall protection (see Attachment C, AIR's Security Policies for Hosting External Systems).

Access to the survey data will be restricted by password to designated analysts.

The following message will be stated on all e-mail invitations to potential respondents, as well as on each page of the survey: "Your answers will be kept completely confidential and not linked to personal or identifying data of any kind. Moreover, your information will not be shared with any other party."

The proposed survey was reviewed by the NIH Privacy Act Officer and was determined to be subject to the Privacy Act; the memorandum includes the following statement:

I have determined that the Privacy Act will apply to this data collection which involves the collection of personally identifiable records that are designed to be retrieved by a personal identifier, such as name, age, gender and email address which will be stored temporarily in a database.

The data collection is covered by NIH Privacy Act Systems of Record 09-25-0156, "Records of Participants in Programs and Respondents in Surveys Used to Evaluate Programs of the Public Health Service, HHS/PHS/NIH/OD."

## A.11. Justification for Sensitive Questions

The survey contains no questions of a sensitive nature regarding sexual behavior and attitudes, religious beliefs, salary, Social Security number, use and abuse of alcohol and drugs, psychological problems, or questions about a third party without that person's knowledge; or any other topics that could be reasonably considered sensitive.

#### A.12. Estimates of Hour Burden and Annualized Hourly Costs

The estimated annual respondent burden and costs for this survey are shown in the following tables.

Table 1: Total Respondents and Burden						
Customer Type	n	Frequency	Average Time (Hrs.) Per Response	Annual Hour Burden		
General Public	1 , 0 7 5	0.3 3	0.2	71		
Private Companies	3 3 2	0.3 3	0.2	22		
Public Sector Groups	3 3 2	0.3 3	0.2	22		
Health Professionals	7 1 1	0.3 3	0.2	47		
Totals	2 , 4 5 0			16 2		

Table 2: Annualized Cost to Respondents					
Customer Type	n	Frequency	Average Time (Hrs.) Per Response	Hourly Wage Rate	Respondent Cost
General Public	<u>,</u> 0	, 0 7 . 5 3 3	0.2	\$ 1 5 1 0	\$ 1 , 0 7 1 3 5
Private Companies	3	0 3 . 2 3 3	0.2	\$ 2 6 8 7	\$ 5 8 7 8
Public Sector Groups	3	3 0 2 . 3 3	0.2	\$ 1 7	\$ 3 9 1

				8 7	5 7
Health Professionals	7	0 1 . 1 3 3	0.2	\$ 3 1 2 6	\$ 1 , 4 6 6 9 1
Totals	4	2, 5 0			\$ 3 , 5 1 8 6 1

The justifications and assumptions for the burden estimate are:

- The total population of individuals who ordered NHLBI materials from September 1, 2005, to August 31, 2008 (3-year period) for whom e-mail addresses are available is 35,724.
- A sample of 2,450 respondents will produce 99 percent confidence intervals of no more than +/- 2.5 percent. (This estimate employs a finite population correction.)
- The distribution of customers across the four types is based on actual distribution data for NHLBI orders by type over the preceding 3 years.
- Given that the survey is to be administered once every 3 years, a frequency of one-third was used to represent the annual frequency.
- A series of pretests of two groups of eight people showed that the average time to complete the survey was approximately 12 minutes (STDEV = 2.9 minutes).
- Estimated hourly wages were based on data on median hourly wage levels by occupation from the U.S. Department of Labor for 2007 at <u>http://www.bls.gov/oes/current/oes\_nat.htm#b21-0000</u>.

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

There are no capital or startup costs to respondents related to this data collection. All respondents will have e-mail addresses, and it is therefore assumed they have access to computers and Web-based applications.

There are no operational, maintenance, or purchase of service costs to respondents related to this data collection.

#### A.14. Annualized Cost to the Federal Government

Costs were estimated by using a 4-year period to cover the development, deployment, data collection, and analysis of the initial survey (done in year 1), two intervening years, and the revision and implementation of a subsequent survey in year 4.

It is assumed that a portion of the subsequent survey will be the same or similar to the initial one, and a subset of revised or additional questions will be required.

- It is also assumed that developing the subsequent survey will require fewer labor hours for the managing research scientist and project director to develop the subsequent survey content.
- The costs of administering, collecting, and analyzing data for the subsequent survey will remain at the levels for the initial survey.

The estimated cost of this study for the 4-year period is \$53,989.62, or \$13,497.41 per year. In terms of a 3-year timeframe, this equates to a cost of \$40,492.23. These costs include:

- Development of the survey instrument for which clearance is requested; and obtaining approval for same from NHLBI OCLA management
- Deployment of the survey on WebSurveyor
- Service and maintenance on the survey tool while it is being used for this project
- Development and transmission of e-mail messages to potential respondents requesting their participation and containing the link to the survey
- Data collation and analysis
- Creation of the final written summary report for the NHLBI and presentation of the highlights of findings to the CST and the OCLA

## A.15. Explanation of Program Changes or Adjustments

This is new collection of data.

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

The results of the data collection will be used for internal NHLBI purposes only and will not be published in any journals or other public forums.

- The proposed data collection is not a research study; therefore, there are no hypotheses to be tested with the data collected from this survey.
- Only descriptive statistics will be used to analyze the data. For example, the responses to the survey questions will be collated and results presented in terms of percentage of respondents choosing each possible response.
- Segmentation and comparisons will be performed on how particular groups of respondents—by virtue of self-identification of background in one of the survey questions—answered questions for all respondents.
- Results for questions relevant only to specific groups—by virtue of the skip logic in the WebSurveyor tool—also will be presented.

 In all cases, margins of error will be presented to help determine to what extent the results decisively indicate a preference or trend among respondents.

A summary report entitled "Results of the NHLBI HIC General Survey 2009: Meeting Public Needs for Health Information" will be presented to OCLA management and CST staff in 2009, within 6 weeks of the completion of the data collection. The summary report will be accompanied by a draft "NHLBI Strategic Plan for the Development of Education Materials for Health Professionals and the Public 2009–2012."

Assuming Office of Management and Budget (OMB) approval within 180 days of submission (end of June 2009), the schedule would be as follows:

- July 2009—Testing and deployment of survey online.
- July–September 2009—Series of e-mail invitations sent to potential respondents; completion of survey by respondents.
- September–October 2009—Collection and analysis of survey data.
- October 2009—Presentation of final survey report and draft 3-year Strategic Plan for health education materials development to NHLBI OCLA management.

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

This approval is not requested. The OMB number and expiration date will be displayed on all surveys, forms, applications, etc.

## A.18. Exceptions to Certifications for Paperwork Reduction Act Submissions

No exceptions are requested.