SUPPORTING STATEMENT A For:

Stakeholder Measures and Advocate Forms

at the National Cancer Institute (NCI)

OMB # 0925-0774 Expiration Date: 10/31/2024

This is a revision to the original submission; all changes are highlighted in yellow.

Date: September 4, 2024

Check off which applies:

- New
- X Revision
- Reinstatement with Change
- Reinstatement without Change
- Extension
- Emergency
- Existing Collection in Use Without an OMB Number

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A. JUSTIFICATION

This is a request for OMB to approve the revised information collection Stakeholder Measures and Advocate Forms at NCI for an additional three years. This revision adds one new survey form. The Office of Advocacy Relations (OAR) disseminates cancer-related information to various stakeholders, seeks input and feedback, and facilitates collaboration to advance NCI's authorized programs. It is beneficial for NCI, through the OAR, to recruit and manage research advocates, which includes collecting demographic information and areas of experience, skill, and interest. Since OAR is responsible for matching advocates to NCI programs and initiatives across the cancer continuum, it is also necessary to measure the satisfaction of both internal and external stakeholders with this collaboration.

A.1. Circumstances Making the Collection of Information Necessary

The National Cancer Institute (NCI) is the Federal Government's principal agency for research, training, health information dissemination, and other efforts related to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and their families [Section 410 of the Public Health Service Act (42 USC *§* 285)].

The NCI Office of Advocacy Relations was established in 1996 in order to promote the Institute's mission and support its programs. The Office of Advocacy Relations (OAR) is NCI's liaison to patient advocacy organizations, individual patient advocates, and professional societies concerned about cancer. The OAR disseminates cancer-related information to these stakeholders, seeks their input and feedback, and facilitates collaboration between the Institute and these external partners to advance NCI's authorized programs [Section 412 of the Public Health Service Act (42 USC *§* 285a-1)]: "The Director of the Institute shall establish and support demonstration, education, and other programs for the detection, diagnosis, prevention, and treatment of cancer and rehabilitation and counseling respecting cancer."

The OAR works with the internal NCI and NIH communities to identify opportunities for patient advocates to participate in NCI and NIH activities. For example, patient advocates participate as volunteers in peer review of grant applications and as members of advisory boards and committees. Once an opportunity is identified, the OAR works with the external advocacy community to identify advocates with the appropriate experience for that particular activity. Although most patient advocates participate in many kinds of advocacy (patient support, fundraising, lobbying, etc.), OAR seeks to identify advocates who work specifically in research advocacy. Given NCI's research mission, advocates who do not have experience in research advocacy may not always be appropriate participants in NCI activities.

The process of engaging advocates in NCI activities has several distinct steps that benefit from program evaluation research and standardized information collection. The steps in the process are:

- Recruitment of advocates
- Providing information and educational opportunities
- Matching advocates to NCI activities
- Tracking and evaluating advocate engagement at NCI
- Promotion of advocate engagement at NCI

Past research has enabled OAR to monitor stakeholder trends, design and develop materials based on user feedback, assess the impact of activities, and improve service delivery. Primary users are internal, with some advocates providing contact information, demographics, and prior advocacy experience via a link provided to them to input their data.

OAR has also requested information from advocates to match them appropriately to NCI activities using the Profile Completion Questionnaire **(Attachment 1)**. Due to the diversity of NCI activities that advocates participate in and the diversity of advocates' experiences and preferences, there are many variables to consider when matching advocates to NCI activities. Individual advocates have submitted resumes or biosketches describing their experiences in research advocacy. The ability to have advocates enter their own research advocate interests and experiences into the database has streamlined the process, allowed for standardization of information collected, and helped avoid documentation errors.

New areas such as nanotechnology, proteomics, and genomics generate new NCI granting opportunities and other activities that involve advocates. It is imperative that OAR have information about advocates' experiences with these new areas to match them to NCI activities appropriately. OAR's database of individual research advocates has been changed to accommodate this new information.

A.2. Purpose and Use of the Information

OAR uses the Profile Completion Questionnaire **(Attachment 1)** to capture applicant information such as basic contact information, age, gender, race and ethnicity, work focus, employment status, health experiences, and research advocacy experience. OAR will continue to use the database system, allowing this information to be collected electronically. Collecting the information electronically is to easily and appropriately match advocates to NCI initiatives and activities and to assist NCI researchers in finding advocates to support their activities. OAR has welcomed 58 advocates into our network in the previous three years. Advocates have contributed to over 60 activities, ranging widely in scope and duration. Several examples include speaking engagements, Task Force appointments, Steering Committee appointments, webinars, Advisory Board appointments, etc.

If there is a successful match, we have the option of conducting a post-activity survey **(Attachment 2**) to the advocates who participated in the activity to ensure they received proper support. We have not conducted any post-activity surveys since the previous approval. In the post-activity survey (**Attachment 3**), respondents may provide information about:

- *Expectations* – To manage expectations, OAR may collect data on whether anticipated beliefs about advocacy performance, extent of participation, and program support were met. For example, "Did your overall contribution to the activity or project meet your expectations?"
- *Facilitators and Barriers* – The OAR strives to facilitate advocate involvement and reduce barriers to it. Items to be measured include program awareness, availability of adequate travel funds, ease of advocate request process, appropriate orientation and activity preparation, and timely follow-up.
- *Recruitment*—A diverse pool of qualified advocates must be recruited and matched to NCI activities based on scientific advances and the subsequent needs of researchers and other staff. The OAR would support its recruitment efforts by identifying "What experiences and skill sets are required of advocates for this activity?" and also by asking advocates if they have these experiences and skills in the administrative forms. Due to natural attrition and changing scientific needs, OAR will need to recruit new advocates to participate in NCI activities continually.
- *Advocate Information* –OAR uses an electronic administrative form to capture basic contact information, such as age, gender, race and ethnicity, work focus, employment status, health experiences, and research advocacy experience. This form will be continually updated and adjusted to meet NCI's changing scientific needs in emerging scientific areas. Additional forms may be used for application to various advocate programs, such as the NCI's only all-consumer advisory board – the NCI's Council of Research Advocates.
- *Satisfaction* –OAR is working to help foster an organizational atmosphere that values the contributions of research advocates. To help determine if this goal is being met, it's important to measure staff satisfaction with the process of requesting advocates, the extent to which advocates abilities and experiences matched the activity, and the overall contribution of the advocate. Advocates and organizations will also provide feedback on their satisfaction working with the NCI and the information they receive from the NCI.

Since the previous approval, OAR has referred over 200 advocates for participation in activities across NCI.

A.3. Use of Information Technology and Burden Reduction

Improved technology in the collection and processing of data has reduced the time burden for respondents and data collectors. Respondents can access and respond to data collection requests at a time and place that is convenient to them, eliminating the need to travel for in-person interviews. Also, individual NCI advocates can update their resume information online at a convenient time and place to them and as often as their experiences and interests change. This eliminates the need for Federal Government staff and contractors to contact advocates individually to determine their interests and experiences with new scientific topics. Wherever possible, NCI will use Web- or computer-based data collection methods. Data collection instruments and responses will be transmitted electronically or facsimile as appropriate. NCI anticipates that the majority of data will be collected electronically. Privacy safeguards will be undertaken with assistance from the NCI Privacy Act Coordinator and the Information Security Office during the data collection process to mitigate any risks.

A Privacy Impact Assessment (PIA) was completed and approved by HHS on April 29th, 2020 **(Attachment 4)**. The IT system's name is "NCI Office of Advocacy Relations (OAR) Research Advocate System (RAS) (P-4190804-047456)."

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

The general areas in which information needs to be gathered (as described in A.2. above) are similar to questions asked previously of NCI stakeholders. However, because advocates are continually paired to new activities with different researchers, measuring these experiences for individual performance, met expectations, facilitators/barriers, and satisfaction does not impose unnecessary duplication. Currently, no similar information would serve the agency's needs and purpose.

The administrative forms will collect demographic information and assess research advocates' experience, skills, and interests. This information is only available from the research advocates and cannot be found anywhere else. Having an administrative form to collect this information will lessen the burden hours required for advocates to submit information to become involved in NCI activities.

A.5. Impact on Small Businesses or Other Small Entities

Small businesses that are non-profits and independently owned may be participants in this submission. The small businesses we may include are physicians, other health care providers, and highly specialized individuals for evaluation of NCI's communication

information and customer satisfaction materials. When small businesses are asked to complete an information collection, all efforts will be made to reduce their burden.

A.6. Consequence of Collecting the Information Less Frequently

Stakeholder satisfaction information will be collected only once for each material tested or completed activity. Administrative forms about the experience of research advocates will be completed once initially for each advocate and then updated by the advocate when they believe it is appropriate. However, there may be occasion where a pre- and post-test to assess differences in knowledge, attitudes, or practices may be useful for a particular sub-study. Additionally, previous respondents may be contacted to participate in follow-up studies if they have originally granted consent for such and if the subsequent study uses that population.

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

There are no special circumstances.

A.8.1 Comments in Response to the Federal Register Notice

The 60-day Federal Register notice was published on May 30, 2024, in Vol. 89, No. 105, Page 46894. No public comments were received.

A.8.2 Efforts to Consult Outside Agency

The questionnaires previously used by OAR were developed with consultation from several scientists and research advocates. External stakeholders helped craft current research instruments for OAR.

A.9. Explanation of Any Payment or Gift to Respondents

No incentives will be given.

A.10. Assurance of Confidentiality Provided to Respondents

Information provided by respondents will be kept secure to the extent provided by law. This will be communicated to respondents using introductory letters, explanatory texts on the cover pages of questionnaires, scripts read before focus groups, and consent forms.

Respondents will also be advised of the following: the nature of the activity, the purpose and use of the data collected, NCI sponsorship, and the fact that participation is voluntary at all times. Because responses are voluntary, respondents will be assured that there will be no penalties if they decide not to respond to the information collection or to any particular questions.

As a further guarantee of security, all presentation of data in reports will be in aggregate form, with no links to individuals preserved. Reports will be used only for research purposes and to develop communication messages and educational materials. Only NCI staff and contractor personnel conducting the information collection will have access to the Advocate Profile information and individual-level surveys. All project/contractor staff conducting the information collection will sign a confidentiality agreement, and all electronic and hard-copy data will be maintained securely throughout the information collection and data processing phases. While under review, electronic data will be stored in locked files on secured computers; hard-copy data will be maintained in secure building facilities in locked filing cabinets. Before any data are released for public use data sets, any identifying information will be stripped from each respondent's record, and the identifying information will be destroyed.

The NIH Privacy Act Officer has reviewed the work scope of this proposal and has determined that the Privacy Act applies to this data collection and 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" (**Attachment 5**).

Personally identifiable information (PII) will be collected (see Section A.11 for further details). Although some PII will be collected, data will not be retrieved by personal identifiers unless the respondent voluntarily agrees to provide the information so he/she can be contacted for follow-up. Instances could arise for activities such as gathering and retaining respondent names and contact information.

A.11. Justification for Sensitive Questions

As mentioned in sections A.2. and A.10., some studies require including people who match selected characteristics of the target audience that NCI is trying to reach. Therefore, PII such as gender, age, race/ethnicity, address, telephone number, email address, education, medical/health status, occupation, and ability to travel must be asked on the initial screening questionnaire used for recruiting. Potential participants are informed that this is being done to ensure that NCI speaks with the kinds of people for whom its messages are intended. Again, respondents are assured that the information is voluntary and will be kept secure to the extent

provided by law. All information on race/ethnicity will comply fully with the standards of OMB.

A.12.1 Estimated Annualized Burden Hours

The number of respondents will vary depending on the nature of the NCI activity involving advocates, the topics being addressed, and the number of advocates recruited to NCI. Table A.12-1 below provides an example of a distribution of respondents and hours by type of data collection. It is estimated that there will be 42 respondents annually, for a total annual burden hour of 17. The NCI anticipates that over the three-year life of the project, there will be a total of 108 respondents, amounting to a burden of 48 hours.

Table A.12-1 Estimated Annualized Burden Hour

Form Name	Type of Respondent	Number of Respondents	Number of Responses per Respondent	Average Burden Per Response (in hours)	Total Annual Burden Hours
Profile Completion	Individuals	30	1	30/60	15
Survey - Advocate	Individuals	6	1	5/60	1
Survey - Requester	Individuals	6	**1**	5/60	**1**
Totals			**42**		**17**

A.12-2: Annualized Cost to the Respondents

The annualized cost to the respondents is estimated to be **$672.69.**

Table 12-2 Annualized Cost to the Respondents

Type of Respondents	Total Annual Burden Hours	Hourly Respondent Wage Rate*	Respondent Cost
Individuals	17	$39.57	$672.69
Total			**$672.69**

The wage rate of $39.57/hour was calculated by averaging the mean wage rates from the Bureau of Labor Statistics for the following occupation codes: All Occupations (occupation code 00-0000) of $34.48/hour, the Medical Scientists rate (occupation code 19-1040) of $53.29/hour, Miscellaneous Life, Physical, and Social Science Technicians (occupation code 19-4099) of $30.95/hour. http://www.bls.gov/oes/current/oes_nat.htm#00-0000.

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

There is no additional cost burden to the respondents and record keepers.

A.14. Annualized Cost to the Federal Government

The estimated annual cost to the government is **$6,580.75**.

Cost Descriptions	Grade/Step	Salary**	% of Effort	Fringe (if applicable)	Total Cost to Gov't
Federal Oversight					
Director	15/10	$191,900	0.5%		$ 959.50
Staff Assistant	12/05	$112,425	5%		$5,621.25
Contractor Cost					$0
Travel					$0
Other Cost					$0
Total					**$6,580.75**

**The Salary in the table above is cited from the Office of Personnel Management https://www.opm.gov/policy-data-oversight/pay-leave/salaries-wages/salary-tables/pdf/2024/DCB.pdf

A.15. Explanation for Program Changes or Adjustments

We added one new survey by splitting up our precious survey into two. We now have one for the Requestor (Attachment 3) and one for the Advocate (Attachment 2).

Changes to the burden are for the following reasons: The number of respondents was reduced from 15 to 6; we added a staff assistant, which increased the Federal cost; other changes were annual updates to BLS and Federal wage figures.

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

OAR staff will search the data to match advocates to NCI activities, including examining their experience in advocacy and cancer research. The number of activities at the Institute and the number of advocates participating in these activities may be published in an OAR newsletter.

While the primary purpose of all OAR studies is to provide information to improve programs and activities, NCI shares information internally and makes results available to various health program planners at Government agencies, voluntary organizations, health professional organizations, and medical institutions. Internal information may include respondent demographics, basic descriptive data, demographic and stakeholder subgroup comparisons, and recommendations for improving programs and products.

A.16.1 Project Time Schedule

Activity	Months after OMB Approval
Complete profile online (collect information)	Ongoing
Review profiles	Ongoing

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

There is no request for exemption from displaying the expiration date for OMB approval.

A.18. Exceptions to Certification for Paperwork Reduction Act Submissions

There are no exceptions to the Certification for Paperwork Reduction Act Submissions.