

OMB SUPPORTING STATEMENT

National Survey of Organ Donation Attitudes and Practices

Submitted by:

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A. Justification

1. Circumstances Making the Collection of Information Necessary

As of August 2011, nearly 112,000 candidates were awaiting organs for transplantation in the United States. At current rates, approximately 28,000 transplants will occur this year, and about 14,000 organs will be recovered from living and deceased donors (<http://optn.transplant.hrsa.gov>). Although progress has been made in the past two decades, thousands continue to die each year because of the unavailability of suitable organs due to reluctance by many to become donors. Organs can be donated while the donor is alive or within several hours of death. In 2010, deceased donors (7,942) outnumbered live donors (6,563), which has been the case since 2004. Most deceased donors were in good health but died suddenly from fatal neurologic injuries, primary central nervous system events, cerebrovascular accidents, subarachnoid hemorrhage, brain tumors or injuries, accidents, drug overdose, smoke inhalation, suicide, or cardiac arrest. Living donors can donate bone marrow, a kidney, and portions of the lungs, and liver. Most living-donor transplants are performed for a relative of the donor.

The research planned for 2011 is intended to extend and expand upon prior surveys about organ donation and practices, especially those conducted in 2005 and 1993 by the Gallup Organization. The survey will support initiatives of the Health Resources and Services Administration's (HRSA) Division of Transplantation (DoT) and related activities of others in the donation community, especially in seeking to alleviate the shortage of donors. Findings also will support efforts of the Organ Procurement and Transplantation Network (OPTN) that is supported and monitored by DoT to ensure an equitable and efficient national system of organ allocation. As in prior years, the survey data and derived analytic insights will help HRSA/DoT develop and target appropriate messages for public outreach and educational initiatives. Understanding the public's perceptions, past practices, and behavioral intentions with regard to organ donations is vital to these efforts. In addition, the survey can provide an approximate gauge of the effectiveness of prior strategies implemented to help promote donation.

The new survey will be carefully designed and executed to produce results that are representative of U.S. adults 18 and older. The survey will consist of at least 3,250 respondents and include supplemental samples of racial/ethnic minorities to ensure that there are sufficient cases for reliable analysis of those groups. The survey will be conducted by telephone in English and Spanish, with interviews lasting about 18 minutes, on average (as in the 2005 survey), and include many questions asked in prior years to facilitate assessment of changes over time. It also includes new questions to address emerging issues. A first-time element of the design will incorporate persons called on their cell phones, since the "cell-only" and "cell-mostly" groups make up an increasing share of U.S. adults (and are not randomly distributed in the population). The survey has been edited and approved by HRSA's Project Officer. Contractor responsibilities include preparation of applications to achieve Office of Management and Budget (OMB) and Institutional Review Board (IRB) approvals. Following the survey interviewing and data processing, a detailed analysis and report will be prepared and presented to HRSA along with an electronic copy of the database (survey data file).

Gallup has been a leader in assessments of public attitudes regarding organ donation, beginning with the initial Gallup poll on the topic in 1968, just weeks after the first heart transplant was performed in South Africa.

2. Purpose and Use of Information Collection

The overall purpose of this study is to conduct an independent telephone survey of public opinion regarding various issues related to organ and tissue donation. The survey will measure public opinion on issues such as financial incentives for donation, living donation, impediments to donation, and level of public knowledge about donation. The goal is to complete 3,250 telephone interviews with adults (18 years of age or older) nationwide. Specifically, this will include 1,250 interviews with a nationally representative sample of U.S. adults plus 500 interviews each with African Americans, Asians, Hispanics and Native Americans.

- The survey will replicate a number of questions asked in a 2005 survey conducted by The Gallup Organization and will provide HRSA/DoT and others in the federal government with responsibilities related to organ donation, as well as the transplant community at large, with updated information on public opinion surrounding willingness to donate.
- Additionally, conducting a survey to assess national attitudes about donation and obtaining public input regarding newer, and in some cases untried, ways to increase donation is useful as the transplant community continues to engage in numerous and increasingly sophisticated efforts to generate public support for donation. The data from this study will provide an overall assessment of the impact of previous outreach efforts and direction and guidance for populations to target and the creation of additional campaign messages and intervention strategies. Data also may be used to inform the development of policy related to organ donation and transplantation.

3. Use of Improved Information Technology and Burden Reduction

The mode of data collection is computer-assisted telephone interviewing (CATI), including both landline and cell phones. Cell phones were not part of the sampling strategy in prior studies (conducted in 1993 and 2005). They will be introduced in this round for the first time to eliminate any possible bias due to non-coverage of this important segment of the target population. Respondent burden is minimized by having a verbal response survey with no written, mail-back, or other requirements for respondents that will take only about 18 minutes of their time.

4. Efforts to Identify Duplication and Use of Similar Information

The Department of Health and Human Services is the only Cabinet Department with statutory responsibility for organ donation. Within the HHS, responsibility for implementing efforts to increase organ donation, is delegated to HRSA/DoT as overseer of the OPTN. To the best of our knowledge, no other entity within the Federal Government has implemented or is planning to implement a national representative survey of the public's donation knowledge, attitudes, and

behaviors related to organ donation and transplantation. Similarly, we are not aware of any private sector group that has implemented or is planning to implement a national representative survey with the same oversamples as this proposed survey.

5. Impact on Small Businesses or Other Small Entities

No small businesses will be involved in this study.

6. Consequences if Collecting the Information Less Frequently

This is an infrequent survey that the program anticipates supporting approximately every 5 years. The previous administration of this survey took place in 2004/2005. It is anticipated that another administration will be conducted around 2017. Less frequent administration of this survey would have a negative impact on practice and policy. The data from this survey are crucial for understanding -- in a rapidly changing health environment -- how best to reach the public with the donation message, encourage more individuals to register as organ donors, and create or modify public policy related to donation and transplantation. Specifically, a longer hiatus between administrations would preclude evidence-based decision-making. Current decisions would be made and programs would be created and implemented based on old data; it would be difficult to associate any changes in public attitudes and behaviors with specific outreach efforts and campaigns; and it would impede the timely identification of, and proactive attention to, population trends and circumstances that may impact public willingness to donate..

7. Special Circumstances Relating to the Guidelines in 5 CFR 1320.5

This information collection fully complies with 5 CFR 1320.5(d)(2).

8. Comments in Response to the Federal Register Notice

A 60-day notice was published in the *Federal Register* on Jan. 7, 2011, Vol. 76, No. 5.. There were no public comments.

9. Explanation of Any Remuneration to Respondents

No remuneration will be given to respondents.

10. Assurance of Confidentiality Provided to Respondents

In accordance with the Privacy Act of 1974, the interviewer will read to each respondent a statement informing him or her under what authority the data are being collected, that cooperation is voluntary, that responses will be used to produce statistical summaries only, and that it will be impossible to identify individuals from their responses.

The file system for this study has been devised to provide maximum protection for confidentiality. At the completion of the data collection, the respondent's telephone number (the

only identifying information) will be separated from the answers to the survey questionnaire.

The file(s) of survey results will be used only for statistical purposes. The files will be sent to the government at the conclusion of the study and will allow for summary data analysis and for proper estimation of sampling errors.

11. Justification for Sensitive Questions

There are no questions of a sensitive nature.

12. Estimates of Annualized Hour Burden

The survey has been designed to minimize burden on respondents (respondents in this study are individuals.) The time that a respondent takes to complete a survey has been carefully considered and only the most important issues are being surveyed. The majority of the items are the same items that were included in the 2005 survey, with some minor edits, to enable analysis of trends over time. The total number of completed surveys will be 3,250 including the oversamples, and survey completion is expected to average about 18 minutes. Therefore, 3,250 respondents times 3/10 of an hour (i.e., 18 minutes) would equal a total of 975 hours.

Burden Estimates for Telephone Survey

	No. of Respondents	Annual Frequency per Response	Total Annual Responses	Hours per Response	Total Hours
Telephone Survey	3,250	1	3,250	.3	975
TOTALS					975

13. Estimates of Total Annual Cost Burden to Respondents

There are no operation and maintenance costs for respondents.

14. Annualized Cost to the Government

The cost of the study for Government personnel is estimated at \$21,884 for two years for an estimated annualized cost per year of \$10,942 (8 percent FTE @ \$136,771 = \$10,942 per year). The estimated government cost for a contract to carry out this study is \$596,921.98. This cost is for roughly 5,716 person hours of which 22 percent are professional hours and 78 percent are support hours (of which 70 percent are interviewing hours).

15. Explanation for Program Changes or Adjustments

The burden per respondent (.3 hours) will be the same as it was in the prior rounds (1993 and 2005) of this survey. However, there is an increase in the number of overall respondents selected for the survey.

16. Plans for Tabulation and Publication and Project Time Schedule

Time Schedule: The final report is scheduled for August 2012.

Publication: The contractor will develop the initial reports from the study findings. HRSA/DoT will use these data in ongoing activities of analyzing and responding to issues on organ donation.

Analysis Plan: The report will provide tabulations at the national level as well as for individual minority groups. It will include an executive summary along with detailed findings about factors related to donation practices, willingness to donate, and attitudes toward organ donation broken out by important demographic categories. Survey data will be weighted to minimize bias in the survey based estimates and the analysis will be based on weighted data.

17. Exemption for Display of Expiration Date

The expiration date will be communicated.

18. Exceptions to Certification for Paperwork Reduction Act Submissions

There are no exceptions to the certification.

Reference

Robert J. Casady and James, M. Lepkowski (1993). Stratified Telephone Survey Designs. *Survey Methodology*, 19, 103-113.

O'Rourke, D. & Blair, J. (1983): Improving Random Respondent Selection in Telephone Surveys. *Journal of Marketing Research*, 20, 428-432.

Kennedy, Courtney (2007): Evaluating the Effects of Screening for Telephone Service in Dual Frame RDD Surveys, *Public Opinion Quarterly*, Special Issue 2007, Volume 71/Number 5: 750-771.