Supporting Statement A

National Survey of Organ Donation Attitudes and Practices <u>Extension</u>

OMB Control No. 0915-0290

Terms of Clearance: None

A. Justification

1. Circumstances Making the Collection of Information Necessary

Patients in need of organ transplantation in the U.S. face a longstanding critical shortage of organs. Approximately 107,000 Americans were on the waiting list for transplantation by the end of 2020, but only approximately 39,000 transplants were performed from both deceased and living donors in 2020. While the number of organ transplants from deceased donors (more than 33,300) sets a new record for the tenth year in a row, the organ shortage still persists across the nation. Understanding the attitudes of the American public in regards to organ donation and transplantation is critical in this ongoing effort to encourage more Americans to donate their organs to close the gap between the number of individuals on the organ transplant waiting list and the supply of donated organs.

Sponsorship of the National Survey of Organ Donation Attitudes and Practices is one of the services HRSA provides to the larger donation community, consistent with HRSA's legal authority to establish a public education and awareness program (section 377A of the Public Health Service Act, 42 USC 274f-1). This type of information is essential for planning, targeting, and implementing outreach efforts to increase public donation commitment as well as for tracking the results of such efforts over time. Members of the donation and transplantation community make use of the findings of these national surveys in their outreach and research efforts. Four national donation attitudes/practices surveys have been conducted to date, 1993, 2005, 2012, and 2019.

The survey produces results that are representative of U.S. adults 18 and older, with enough responses from racial/ethnic sub-groups and adults over the age of 65 to make reliable statistical comparisons. The survey consists of at least 10,000 respondents. The survey is conducted by online and telephone modes in English and Spanish, with interviews lasting about 17.4 minutes.

Following the survey interviewing and data processing, the contractor will provide to HRSA a detailed analysis and report along with an electronic copy of the database (survey data file).

2. Purpose and Use of Information Collection

The overall purpose of this study is to conduct an independent multi-mode (web and telephone) survey of public opinion regarding various issues related to organ donation. The survey will measure public opinion on issues such as willingness to become an organ donor, financial incentives for donation, living donation, impediments to donation, and level of public knowledge about donation. The goal is to complete 10,000 interviews with adults (18 years of age or older) nationwide. Specifically, this will include 1,000 equal-probability of selection method (EPSEM) computer-assisted telephone interviewing (CATI) interviews, 1,000 ethnic oversample CATI interviews, and a supplemental web panel of 8,000 respondents. The final sample will include 1,000 interviews each with African Americans, Asians, Hispanics and Native Americans, and statistically sufficient sample for meaningful comparisons across demographic levels of age group, education, and income groups. The total sample of 10,000 is necessary to achieve sufficiently large subgroups for statistical analysis across demographic groups.

3. Use of Improved Information Technology and Burden Reduction

The modes of data collection are web survey and CATI interviews, including both landline and cell phones. Respondent burden is minimized by having automatic data entry either electronically by the respondent answering the online survey or by a trained CATI interviewer for a telephone survey that includes no additional requirements for respondents. The survey has been designed to capture only the minimum necessary information for analysis and takes only about 22 minutes of the respondent's time for the CATI survey and 16 minutes for the web survey. The questions are the same in both the CATI and web surveys.

4. Efforts to Identify Duplication and Use of Similar Information

The Department of Health and Human Services is the only department with statutory responsibility for solid organ donation. Within HHS, responsibility for administering the national organ transplantation program including efforts to increase organ donation is delegated to the Division of Transplantation within HRSA DoT. 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 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 a similar oversampling strategy as proposed for this survey.

5. Impact on Small Businesses or Other Small Entities

This is a survey of a representative sample of the U.S. population over the age of 18. No small businesses will be involved in this study.

6. Consequences of Collecting the Information Less Frequently

This is an infrequent survey that HRSA anticipates supporting approximately every 5-7 years. The previous administration of this survey took place in 2019 and before that in 2012 and 2005. We anticipate that another administration will be conducted around 2024. 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 to most effectively craft message to the public regarding organ donation in order to encourage more individuals to register as organ donors, and create or modify public policy related to donation and transplantation. Specifically, a longer time 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. There are no legal obstacles to reduce the burden.

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

The request fully complies with the regulation.

8. Comments in Response to the Federal Register Notice/Outside Consultation

Section 8A:

A 60-day Federal Register Notice was published in the *Federal Register* on April 16, 2021, vol. 86, No. 73; pp. 20374 (see attachment 60-day FRN). No comments were received.

9. Explanation of any Payment/Gift to Respondents

Respondents will not receive any payments or gifts.

10. Assurance of Confidentiality Provided to Respondents

In accordance with the Privacy Act of 1974 all potential respondents will either see (if replying via web) or hear (if replying via telephone) 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. We will inform respondents "Data will be kept private to the extent allowed by law."

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 and address (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, except for race and ethnicity. These questions are required to support analysis of demographic subgroups. Because organ transplantation attitudes vary across racial and ethnic categories, and race/ethnicity is a key sample stratification, this is considered an essential question for this research. Respondents are anonymous and are free to decline to answer any questions they choose.

12. Estimates of Annualized Hour and Cost 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 items are the same items that were included in the 2019 survey. The total number of completed surveys will be 10,000 including the oversamples, and survey completion is expected to average about 17.4 minutes. This includes 2,000 phone respondents with an estimated average of 22 minutes (.37 hours) and 8,000 web cases with an estimated completion time of 16 minutes (.27 hours).

12A.Estimated Annualized Burden Hours

Type of Respondent	Form Name	No. of Respon dents	No. Responses per Respondent	Average Burden per Response (in hours)	Total Hours
Adults over the age of 18	National Survey of Organ Donation Attitudes and Practices –Telephone (English and Spanish Versions)	2,000	1	.37	740
Adults over the age of 18	National Survey of Organ Donation Attitudes and Practices –Web Online Panel (English and Spanish Versions)	8,000	1	.27	2,160
Total		10,000			2900

12B.
Estimated Annualized Burden Costs

Type of Respondent	Total Burden Hours	Hourly Wage Rate	Total Respondent Costs
Adults over the age of 18	2900	\$24.34	\$70,586.00
Total	2900		\$70,586.00

The mean hourly wage from the Department of Labor National Occupational Employment Statistics was used to estimate the annualized burden costs.

13. <u>Estimates of other Total Annual Cost Burden to Respondents or Recordkeepers/Capital Costs</u>

Other than their time, there is no cost to respondents.

14. Cost to Federal Government

The cost of the study for government personnel is estimated at \$36,180 over two years (10 percent full time equivalent at \$361,800 = \$36,180). The estimated government cost for a contract to carry out this study is \$600,000. This cost is for roughly 8,228 person hours of which 25 percent are professional hours and 75 percent are support hours (of which 55 percent are interviewing hours).

Estimated Costs of Study

	Governmen t Personnel Cost	Estimated Contract Cost	Total
Cost to Federal Government	\$36,180	\$600,000	\$636,180

15. Explanation for Program Changes or Adjustments

No proposed changes for this extension and the burden estimate remains the same.

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

HRSA anticipates awarding a contract in FY 23/24 to administer this survey.

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

The OMB number and Expiration date will be displayed on every page of every form/instrument.

18. Exceptions to Certification for Paperwork Reduction Act Submissions

There are no exceptions to the certification.