

Health Resources and Services Administration
SUPPORTING STATEMENT
HRSA Division of Transplantation (DoT) Formative Evaluation
Minority Organ Donation Outreach

A. Justification

1. Circumstances of Information Collection

The Health Resources and Services Administration (HRSA) currently has approval under the generic clearance, Office of Management and Budget (OMB) Control No. 0915-0212, to conduct customer satisfaction surveys and focus groups. This collection of information helps fulfill the requirements of:

- a. Executive Order 12862, “Setting Customer Service Standards,” which directs Agencies to continually reform their management practices and operations to provide service to the public that matches or exceeds the best service available in the private sector.

This is a request for OMB approval of a qualitative voluntary customer satisfaction survey or focus group under HRSA’s generic clearance.

HRSA’s Division of Transplantation (DoT) is requesting approval to conduct a series of sixteen (16) online qualitative focus groups with customers, as well as to conduct a qualitative customer satisfaction survey for visitors to its website at www.organdonor.gov who indicate interest in registering to become an organ and tissue donor. By qualitative feedback, we mean information that provides useful insights on perceptions and opinions, not statistical surveys that yield quantitative results that can be generalized to the population of study.

Executive Order 12862 directs agencies that “provide significant services directly to the public” to “survey customers to determine the kind and quality of services they want and their level of satisfaction with existing services.”

DoT will obtain feedback from customers and potential customers related to its outreach materials on organ donation and transplantation for minority audiences. These materials are a vital part of DoT’s mission to extend and enhance the lives of individuals with end-stage organ failure (Organ Donation and Recovery Improvement Act, 42 USC 201SEC 377A (a)).

This collection of information is necessary to enable the Agency to garner customer feedback in an efficient, timely manner, in accordance with our commitment to improving service delivery and increasing the number of donors. Minority donors such as African Americans; Asian, Native Hawaiian, or other Pacific Islanders; Hispanics; and American Indians/Alaska Natives are particularly important to DoT’s outreach efforts because these populations are over-represented on organ recipient waiting lists. These minority groups are also more likely to suffer from health disparities that increase their chances of needing an organ transplant. Minority audiences have unique information needs along with established barriers to organ donation that DoT needs to appropriately address in its communication materials and outreach efforts.

The information collected will help ensure that users have an effective, efficient, and satisfying experience with DoT's materials and programs. These collections will allow for ongoing, collaborative, and actionable communications between DoT and its customers.

2. Purpose and Use of the Information

Improving agency programs requires ongoing assessment of service delivery in the form of systematic review of the operation of a program compared to a set of explicit or implicit standards as a means of contributing to the continuous improvement of the program. As a vital part of its ongoing mission, DoT produces outreach and information materials on organ donation and transplantation for numerous audiences, including minority audiences. These materials respond to and anticipate customer needs and requirements, including providing information about organ donation and instructions on how to register to become an organ donor. HRSA will only use the information gathered for internal purposes in an effort to gain a better understanding of DoT outreach and information materials.

DoT is seeking feedback on new materials specifically designed for minority audiences as well as to better understand the needs of minority customers who visit its website. Two types of feedback are planned under this request:

- Online focus group feedback will include areas such as the appropriateness of outreach materials for minority audiences and accuracy of the information provided. Responses will be used to finalize materials for dissemination.
- Online survey feedback will focus on satisfaction with the site as well to collect information from new registrants on why they decided to register and whether they have seen/heard anything recently on organ donation that influenced their decision. These data will help to inform future outreach campaigns, as well as to provide information to evaluate the success of existing efforts to reach prospective donors.

If this information is not collected, vital feedback from customers will be unavailable, and DoT may develop and distribute materials that are confusing or not motivating.

The collection of this information will be qualitative, voluntary, and non-controversial. Collection will be targeted to the opinions of customers who support organ donation and would consider registering as donors but have not yet done so, as well as to website visitors who indicate a desire to register as donors.

DoT is requesting generic clearance to conduct:

- Sixteen online focus groups of customers and potential customers with a focus on minority audiences.
- An online survey with website visitors who indicate that they intend to register as organ donors.

These qualitative research approaches will provide DoT with the information it needs to improve its materials and service delivery.

3. Use of Improved Information Technology

The focus groups will be conducted online, which is an effective methodology to obtain feedback from respondents and to reduce overall burden and project costs. Online sessions will allow for in-depth exploration of themes and reactions to materials. We have limited the number of sessions to reduce the overall burden, while ensuring we speak to a sufficient number of individuals to represent each audience. Focus group feedback will be 100 percent electronic, as the most efficient and least burdensome method to reach this audience.

Website feedback will be obtained online via a short, opt-in survey for those to indicate a desire to register as organ donors (i.e., those who visit <https://www.organdonor.gov/register.html>). The use of technology will reduce burden by only contacting potential respondents who are already visiting DoT's website. Website feedback will be 100 percent electronic as this is the most efficient and least burdensome method to reach this audience.

4. Efforts to Avoid Duplication

The Department of Health and Human Services is the only cabinet department with statutory responsibility for organ donation. Within the Department of Health and Human Services, responsibility for implementing efforts to increase organ donation is delegated to DoT. To the best of our knowledge, no other entity within the federal government has gathered or is planning to gather similar data. The attached qualitative instruments have been reviewed carefully to avoid potential duplication.

5. Involvement of Small Entities

No small businesses will be involved in this study.

6. Consequences if Information Collected Less Frequently

This feedback is to inform an effort DoT is making to improve its outreach to minorities on organ donation. This is a current focus of DoT. DoT has received negative feedback on some of its past communications with minority audiences, and has identified a need for research to improve materials. The online focus groups are designed to support this effort. Likewise, the web survey is a one-time effort to inform overall outreach efforts to better understand what information is most impactful for potential donors. Without this information, DoT's website will not be as effective in providing crucial information to customers.

7. Consistency With the Guidelines in 5 CFR 1320.5(d)(2)

These surveys will be implemented in a manner fully consistent with 5 CFR 1320.5(d)(2).

8. Consultation Outside the Agency

In accordance with 5 CFR 1320.8(d), on November 13, 2017, a 60 day notice was published in the Federal Register for HRSA's generic clearance, OMB Control No. 0915-0212 (Vol. 82, No.

217, pp. 52308-09). No public comments were received.

9. Remuneration of Respondents

This request involves online focus groups and completion of an online survey. DoT will provide a stipend of \$100 for participants in 90-minute online focus groups. These stipends are necessary to ensure the validity of research findings, as potential respondents are likely to be unwilling to participate in these research activities without receiving compensation for their time. Online web respondents will not be offered remuneration.

10. Assurance of Confidentiality

This assessment does not involve the collection of personally identifiable information except in order to provide compensation for focus group participants. Data collection will fully comply with all aspects of the Privacy Act, and participants will be notified that their research responses will be kept private to the extent allowed by law and that participation is voluntary. Audio recordings of the focus groups will only be made with respondent permission. These recordings will be used solely to verify notes taken for accuracy and then destroyed. Respondents will be assured that neither their participation/non-participation nor any of their responses to items will have any effect on their participation in Agency programs.

No personally identifiable information will be collected for respondents to the online survey.

11. Questions of a Sensitive Nature

As a part of the screening process for selecting focus group research participants, DoT will collect information on race and ethnicity. This information is necessary since the research focus specifically relates to materials for minority audiences. Many of these audiences are disproportionately represented on transplant waiting lists and have had well documented health disparities. DoT needs to ensure that participants in the sessions can represent the viewpoints of these specific audiences. No other sensitive information will be collected.

The online survey will contain optional questions about race/ethnicity to collect demographic information about survey respondents. These questions will help to ensure that findings can be appropriately applied to inform DoT's materials; collecting such information is a best practice in all HRSA surveys.

12. Estimates of Annualized Hour Burden

Focus groups and an online survey will be used to collect information from respondents. The annual burden hours requested (301.6 hours) are based on the number of collections we expect to conduct over the requested period for this clearance.

Respondents:

We anticipate two types of respondents for this research:

- 1) Online focus group participants will be individuals who support organ donation but who have not registered as organ and tissue donors. Respondents will primarily represent diverse racial and ethnic backgrounds, including respondents who are African American; Asian, Native Hawaiian, or other Pacific Islander; Hispanic; and American Indian/Alaska Native. We are planning sixteen focus groups with six respondents each, for a total of 96 respondents. Each respondent will take part in a 90-minute session, plus 15 minutes for screening time. Each respondent will participate once.

- 2) Online survey respondents will be individuals who visit the online registration page at organdonor.gov. These respondents will be invited to take part in a survey to provide input. We expect about 10 percent of site visitors will take part in the survey and will have the survey on the site for about six months. We anticipate about 800 respondents will take part in the survey. Each respondent will participate once, and each response will take about 10 minutes (0.167 hours).

Annual burden estimates:

Type of Collection	Number of Respondents	Responses per Respondent	Total Responses	Hours per Respondent	Total Burden Hours	Wage Rate	Total Hour Cost
Online focus groups	96	1	96	1.75	168	\$25.72	\$4,320.96
Online survey	800	1	800	0.167	133.6	\$25.72	\$3,436.19
Total	896		896		301.6		\$7,757.15

The anticipated burden is 301.6 hours, comprising 168 hours from focus group respondents and 133.6 hours from online survey participants.

Planned frequency of information collection:

These are one-time data collection activities. Each focus group participant will take part once, and each survey respondent will take part once.

13. Estimates of Annualized Cost Burden to Respondents

No appreciable costs are anticipated for focus group participants. Any out-of-pocket expenses (e.g., phone minutes) would be more than offset by the honorarium. There will be no cost to participate for online survey respondents.

14. Estimates of Annualized Cost to the Government

The anticipated cost to the federal government is approximately \$189,449.90 and is broken out into contract costs and personnel costs of federal employees.

Contract costs are \$180,000 and are comprised of contractor payments for staff time to conduct and analyze the research, recruit participants, distribute stipends, conduct transcription and translation, host focus groups and remote feeds for offsite viewing, and costs for survey hosting.

Personnel costs from federal employees are \$9,449.90, which includes 5 percent from GS-12 (\$86,335) and 5 percent from GS-13 (\$102,663).

15. Change in Burden

Not Applicable. This is a new activity under HRSA's generic clearance and will be included in the total burden currently approved by OMB under OMB Control No. 0915-0212.

16. Plans for Analysis and Timetable of Key Activities

Feedback collected will provide useful information, but it does not yield data that can be generalized to the overall population. Findings will be used to finalize materials for minority populations and to improve the website, but not for publication or other public release.

Although DoT does not intend to publish its findings, DoT may receive requests to release the information (e.g., congressional inquiry, Freedom of Information Act requests). The Agency will disseminate the findings when appropriate, strictly following the Agency's "Guidelines for Ensuring the Quality of Information Disseminated to the Public," and will include specific discussion of the limitation of the qualitative results discussed above.

Data collection will start in or after September 2020. Focus group data will be collected and analyzed over a 5-month period. We anticipate one month to plan the research, two months to field the research, and two months to analyze and report on findings.

The online qualitative survey will be collected and analyzed over a 9-month period. We anticipate one month to plan the research, six months to field the study, and two months to analyze and report on findings.

17. Exemption for Display of Expiration Date

No exemption is being requested. The expiration date will be displayed.

18. Certifications

This information collection activity will comply with the requirements in 5 CFR 1320.9.