

**Health Resources and Services Administration (HRSA)
Healthcare Systems Bureau, Division of Transplantation (DoT)
Discussions on 50+ Donors
SUPPORTING STATEMENT**

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 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 voluntary customer satisfaction survey and focus groups under HRSA’s generic clearance.

HRSA’s Division of Transplantation (DoT) is planning to conduct an outreach effort targeting the 50+ population to encourage them to learn more about organ donation and to consider registering as organ donors. To inform this outreach effort, HRSA will query members of the target population through surveys and focus groups on their information needs related to organ donation and preferred communication channels. DoT will use the findings to develop outreach materials to educate the 50+ population about organ donation.

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.” This data collection activity is designed to obtain information to allow DoT to fulfill this objective.

Adults aged 50 and older need and receive a significant share of donated organs. As of the end of December 2016, people aged 50+ represented 66.9 percent of the national organ waiting list and received 61.9 percent of all transplants. Yet, 50+ adults are under-represented as donors. In 2016, only 33 percent of all donors were 50 and older. Similarly, a 2012 national survey conducted by HRSA found that those aged 66+ were less likely to have agreed to be a donor compared with younger age groups.

Key questions to be addressed by this project include:

- What do 50+ adults know about organ donation?
- What do they know about how organs are allocated?
- What information would they like to know about donation to inform their registration decisions?
- Where do they get information on organ donation?
- Where do they want to get information on organ donation?
- What kind of messaging is most helpful to 50+ adults?

2. Purpose and Use of the Information

The purpose of this request is to collect information about the 50+ population's knowledge of and attitudes toward organ donation; where and how they prefer to receive information; and their preference for different types of messaging. As a vital part of its ongoing mission, HRSA produces outreach materials on organ donation and transplantation for numerous audiences, including both consumer and professional audiences. This information is valuable to HRSA in developing new organ donation outreach materials and refining and improving existing materials to maximize their impact.

HRSA is, therefore, seeking to gather pertinent information about the 50+ population. Information gathered will relate to the topic of communications (what information customers would like), format (what is the best method to convey the information), and delivery method (how to reach customers with information). Responses will directly inform and improve the communications DoT has on this topic. This vital, formative information will enable DoT to communicate efficiently and effectively about this topic with this audience.

The collection of this information will be voluntary and non-controversial. Collection will be targeted to the opinions of adults who support organ donation and would consider registering as donors but have not yet done so. Participants will be aged 50-80.

HRSA is requesting generic clearance to gather formative information to improve its service delivery using two data collection methods:

- Focus groups (2) of potential customers to inform product development and refinement
- A satisfaction and preference survey of potential customers to determine how framing impacts attitudes and intentions related to organ donation

Data from the focus groups will be exploratory in nature, and will identify what 50+ adults know and want to know about donation. Data from the survey will shed light on the impact of different communication approaches. For example, is information on donation more useful when presented in a story format or in a more factual presentation? Survey data will be used strictly for internal program planning and development purposes, and are not intended to be statistically representative of any population.

3. Use of Improved Information Technology

The focus groups will not employ information technology but will be conducted in-person, which is the most appropriate and cost-effective methodology to obtain feedback. The design is limited to the smallest number of respondents possible (two groups) to further reduce the overall burden. In-person data collection allows interaction with participants to understand their reactions better than if conducted by phone. A focus group also allows participants to discuss ideas with one another.

The survey will be conducted electronically to reduce burden.

4. Efforts to Avoid Duplication

The Department of Health and Human Services (HHS) is charged with statutory oversight of the organ transplant system in the country including initiatives to increase organ donation and awareness. Within HHS, responsibility for implementing efforts to increase organ donation is delegated to HRSA. To the best of our knowledge, no other entity within the Federal Government has gathered or is planning to gather similar data.

5. Involvement of Small Entities

No small business will be involved in this study.

6. Consequences if Information Collected Less Frequently

HRSA is requesting to collect data from this population only one time through these two focus groups and one online survey. Without this feedback, DoT will not have relevant information to inform the creation of new outreach materials that clearly address customer needs.

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

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

8. Consultation Outside the Agency

On March 6, 2015, HRSA published a Federal Register notice seeking public comment concerning its submission to OMB of a request for an extension of OMB Control No. 0915-0212 (80 Fed. Reg. 12179).

9. Remuneration of Respondents

This request involves two focus groups and a survey. DoT will provide a stipend of \$75 for each focus group participant. These stipends are necessary to ensure adequate participation, as respondents are unlikely to participate without receiving compensation for their time.

Survey participants will receive a small stipend of \$2.00 for participating in accordance with the typical practices of the survey sample provider. Small incentives to complete surveys are standard practice among survey panel companies – different panels compensate members differently.

10. Assurance of Confidentiality

This effort will not involve the collection of personally identifiable information. HRSA will be provided only with first names of focus group participants. DoT will not receive the IP addresses or other identifying information from those who participate in the survey.

Participation is fully voluntary and responses are confidential. Tape recordings of the groups

will be conducted only with respondent permission. These recordings will be used solely to verify the accuracy of notes taken 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 any HRSA program.

11. Questions of a Sensitive Nature

As a part of the screening process for selecting participants, HRSA will collect information on race and ethnicity. This information is necessary since many of these audiences are disproportionately represented on transplant waiting lists and have had well documented health disparities. HRSA will use the information to ensure that the project includes participants of diverse racial and ethnic backgrounds so that information on 50+ donation can effectively speak to these audiences.

12. Estimates of Annualized Hour Burden

Respondents:

Respondents will include individuals who support organ donation. The annual burden hours requested (71) are based on the number of collections expected over the requested period for this clearance.

Annual burden estimates:

<u>Type of Collection</u>	<u>Number of Respondents</u>	<u>Responses per Respondent</u>	<u>Total Responses</u>	<u>Hours per Respondent</u>	<u>Total Burden Hours</u>	<u>Wage Rate</u>	<u>Total Hour Cost</u>
Focus groups	24	1	24	2.25	54	\$20	\$1,080
Online survey	100	1	100	.17	17	\$20	\$340
Total	124	1	124	.57	71	\$20	\$1,420

Each focus group participant will take part in a 2-hour study plus 15 minutes to answer screening questions and to provide informed consent. Each survey participant will take part in a 10-minute study, which includes screening and informed consent.

Planned frequency of information collection:

Each respondent will participate one time.

13. Estimates of Annualized Cost Burden to Respondents

No appreciable costs are anticipated for focus group respondents. Any out-of-pocket expenses (phone minutes, mileage to focus group facility, etc.) would be more than offset by the stipend.

No appreciable costs are anticipated for survey respondents.

14. Estimates of Annualized Cost to the Government

The anticipated cost to the Federal Government is approximately \$37,000. These costs are comprised of:

Contractor payment (which includes recruitment of participants, participant stipends, facility rental, survey hosting, analysis, and reporting): \$35,000 (based on estimate provided by contractor to the government)

Government cost (including supervision of contractors and observing focus groups): \$2,000 (assuming 40 hours at an average rate of \$50/hr.)

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

Data will be collected within 3-4 weeks of OMB approval, estimated April-May 2017. Analysis and reporting will occur in June-July 2017.

Focus group findings will be analyzed using qualitative approaches to inform HRSA's communication efforts. They will not be generalized to the overall population nor will they be used for publication or public release.

Survey findings will be analyzed to make comparisons across groups. Findings will be used to inform HRSA communication approaches, but will not be generalized to the overall population nor will they be used for publication or public release. DoT will use findings to refine content and materials on 50+ donation.

Findings will only be shared and used internally for improvement and will not be generalized to the public. There are no plans for publication of any results.

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.

Attachments:

1. Focus Group Informed Consent
2. Focus Group Guide
3. Focus Group Moderator Guide
4. Focus Group Participant Screener
5. Survey Screener and Questionnaire
6. Survey Form