

**Health Resources and Services Administration**  
**SUPPORTING STATEMENT**  
**HRSA Division of Transplantation (DoT) Discussions on Teen Organ Donors**

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

Teenagers are often asked to consent to organ donation as a part of the process to obtain their first driver’s license. However, teens are often asked to make this choice with limited information – both about the process of registration and what it entails, as well as about organ donation itself and what it means to register as an organ donor.

HRSA’s Division of Transplantation (DoT) is requesting to obtain feedback from teen customers and potential customers on their information needs related to organ donation. DoT will use this information to refine current communication messages, products, and tools to ensure they are relevant and appealing to the U.S teen population.

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 collect information to allow DoT to fulfill this objective.

Key questions to be addressed by this project include:

- What do teens know about organ donation?
- What information would they like to know about organ donation to inform their registration decision?
- Where do teens get information on organ donation?
- Where do teens want to get information on organ donation?
- What kind of messaging on donation is most helpful to teens on organ donation?

## 2. Purpose and Use of the Information

As a vital part of its ongoing mission, DoT produces outreach strategies, messages, and information materials on organ donation and transplantation for numerous audiences, including both consumer and professional audiences. These materials are designed to respond to and anticipate customer needs and requirements, including providing information about organ donation for new or prospective registered donors.

To improve and expand upon existing materials on organ donation for teens,<sup>1</sup> DoT is seeking to gather pertinent information on customer needs. Feedback 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 is vital, formative information, designed to allow DoT to communicate efficiently and effectively on this topic to this audience.

Many teens have limited information about organ donation. They may not have encountered any information on this topic before being asked whether they want to register at the DMV. DoT needs to understand how best to provide needed information to customers and potential customers to discuss teen donor registration.

The collection of this information will be voluntary and non-controversial. The collection will be targeted to the opinions of teens who support organ donation and would consider registering as donors but have not yet done so. All teens will be aged 15-17.

Teens will be recruited via the database of a focus group facility – calls will be made to parents, who will assent, and then teens will be screened.

The feedback gained through this effort would help DoT customize its outreach efforts and materials to make them more teen-appropriate and –appealing. Key among DoT’s existing portfolio of products that would be tailored based on the findings are portions of [organdonor.gov](http://organdonor.gov) and its Facebook content by adding graphics and short videos specifically targeting teens.

DoT is requesting generic clearance to conduct qualitative discussions to improve its service delivery:

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

These are the best approaches for enabling DoT to gather the information it needs to improve its materials and service delivery. Data from the focus groups will be exploratory in nature, and will identify what teens know and want to know about donation. Data from the survey will focus

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<sup>1</sup> For examples of existing materials, see <http://www.organdonor.gov/materialsresources/pdf/mpb-carlee-7x10.pdf>, <http://www.organdonor.gov/materialsresources/pdf/mpb-blake1-7x10.pdf>, <https://www.youtube.com/watch?v=y9lO3plJys4&feature=youtu.be>, and [https://www.youtube.com/watch?v=WYaKE3j\\_Axs&feature=youtu.be](https://www.youtube.com/watch?v=WYaKE3j_Axs&feature=youtu.be).

on the impact of different communication approaches. For example, is information on donation more accessible to teens when it is presented in a story format or in a more factual presentation? Survey data will be used strictly for internal program planning purposes, and are not intended to be statistically representative of any population.

DoT will use the information collected as it refines communications on this topic, currently planned for the fiscal year 2017. If these data are not collected, vital feedback from customers on the Agency's services will be unavailable.

### 3. Use of Improved Information Technology

The survey will be conducted electronically to reduce burden.

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 from these respondents. We have limited the design to the smallest number of respondents possible (two groups) to reduce further the overall burden. In-person data collection allows us to interact with participants and better understand their reactions better than if conducted by phone. A focus group also allows participants to discuss ideas with one another.

### 4. Efforts to Avoid Duplication

The Department of Health and Human Services is the only Cabinet Department with statutory responsibility for organ donation. Within HHS, 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 instruments have been reviewed carefully to avoid potential duplication.

### 5. Involvement of Small Entities

No small business will be involved in this study.

### 6. Consequences if Information Collected Less Frequently

Without this type of feedback, DoT will not have access to timely information needed to create new outreach materials that would meet customer needs. Customers will be asked to participate one time, and participation is voluntary. There are no legal obstacles to reducing the burden.

### 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 April 24, 2009, a 30-day notice was published in the Federal Register for HRSA's generic clearance, OMB Control No. 0915-0212 (Vol. 74, Page 18726). No public comments were received.

9. Remuneration of Respondents

This request involves a survey and two focus groups. DoT will provide a stipend of \$5 to each two-hour focus group participant. These stipends are necessary to ensure the validity of findings, as potential respondents are likely to be unwilling to participate in these activities without receiving compensation for their time.

Survey participants will receive a small stipend 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. Since the final panel provider has not yet been selected the amount of this reward has not yet been determined.

Teens will be recruited via the online survey panel. Parents will be asked to assent to their teen participating, and then teens will be screened.

10. Assurance of Confidentiality

To date, HRSA customer satisfaction surveys have not collected personally identifiable information from respondents. Accordingly, this effort will not involve the collection of personally identifiable information. DoT will be provided with only 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 the respondent's permission. These recordings will be used solely to verify the accuracy of notes taken and then they will be 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 Agency programs.

11. Questions of a Sensitive Nature

As a part of the screening process for selecting participants, DoT 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. DoT will use the information to ensure that the project includes participants of diverse racial and ethnic backgrounds so that information on teen donation can effectively speak to these audiences.

12. Estimates of Annualized Hour Burden

*Respondents:*

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

*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
Focus groups	24	1	24	2.25	54	\$20	\$1,080
Online survey	100	1	100	.17	17	\$20	\$340
Total	124		124		71		\$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 June 2016. Analysis and reporting will occur in July 2016.

Survey findings will be analyzed to make comparisons across groups. Findings will be used to inform DoT 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 teen donation.

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

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 Participant Screener
3. Focus Group Moderator Guide
4. Survey Screener and Questionnaire