

Request for Approval under the “Questionnaire and Data Collection Testing, Evaluation, and Research for the Health Resources and Services Administration” (OMB Control Number: 0915-0379)

TITLE OF INFORMATION COLLECTION: Organ Procurement and Transplantation Network (OPTN) Stakeholder Focus Groups

PURPOSE: To improve the organ transplantation patient and provider experience, HRSA will convene focus groups to gather input from these stakeholders to inform future programmatic decisions. Specifically, the information HRSA collects via these focus groups will be used to inform the priority and shape of modernization opportunities.

HRSA anticipates convening focus group sessions across various respondent personas, in line with the Description of Respondents below. Focus group moderators will ask respondents to describe their activities when interacting with the Network. The moderators will only stop respondents to clarify steps of the activities that they describe, or to expand upon pain points.

DESCRIPTION OF RESPONDENTS: OPTN focus group respondents will include:

- Members of the Organ Transplantation Patient Community (e.g., individuals awaiting organ transplants; organ donors; transplant recipients their families; patient advocacy organization representatives)
- Members of the Organ Transplantation Provider Community (e.g. representatives of organ procurement organizations(OPOs)¹, ; histocompatibility labs², and transplant centers³ Provider groups that are members of OPTN are the primary groups that will be critically impacted by modernization of the OPTN and their feedback will be weighted greater than patient members.
- Members of the Organ Transplantation Scientific Research Community (e.g., researchers, academics)

TYPE OF COLLECTION: (Check one)

- | | |
|--|---|
| <input type="checkbox"/> Customer Comment Card/Complaint Form | <input type="checkbox"/> Customer Satisfaction Survey |
| <input type="checkbox"/> Usability Testing (e.g., Website or Software) | <input type="checkbox"/> Small Discussion Group |
| <input checked="" type="checkbox"/> Focus Group | <input type="checkbox"/> Other: |

CERTIFICATION:

I certify the following to be true:

¹ OPOs are non-profit organizations responsible for coordinating organ, tissue, and eye donation within specific geographic areas. OPO staff work closely with donor families and hospitals to facilitate organ donation.

² Histocompatibility labs are specialized laboratories that provide critical testing to assess the compatibility between organ donors and recipients.

³ Transplant center staff includes surgeons, physicians, and nurses, who provide medical care for transplant recipients before and after surgery.

1. The collection is voluntary.
2. The collection is low-burden for respondents and low-cost for the Federal Government.
3. The collection is non-controversial and does not raise issues of concern to other federal agencies.
4. The results are not intended to be disseminated to the public.
5. Information gathered will not be used for the purpose of substantially informing influential policy decisions.
6. The collection is targeted to the solicitation of opinions from respondents who have experience with the program or may have experience with the program in the future.

Name: Manjot Singh

To assist review, please provide answers to the following question:

Personally Identifiable Information:

1. Is personally identifiable information (PII) collected? [] Yes [X] No
2. If yes, will any information that is collected be included in records that are subject to the Privacy Act of 1974? [] Yes [] No
3. If yes, has an up-to-date System of Records Notice (SORN) been published? [] Yes [] No

Gifts or Payments:

Is an incentive (e.g., money or reimbursement of expenses, token of appreciation) provided to participants? [] Yes [X] No

BURDEN HOURS

Category of Respondent	No. of Respondents	Participation Time	Burden Hours Total
Patient Community	40	1 hour	40
Provider Community	45	1 hour	45
Scientific Research Community	15	1 hour	15
Totals	100		100

FEDERAL COST: The estimated total cost of this collection is \$350,000 per HRSA’s contracted task order.

If you are conducting a focus group, survey, or plan to employ statistical methods, please provide answers to the following questions:

The selection of your targeted respondents

1. Do you have a customer list or something similar that defines the universe of potential respondents and do you have a sampling plan for selecting from this universe?
 Yes No

If the answer is yes, please provide a description of both below (or attach the sampling plan)? If the answer is no, please provide a description of how you plan to identify your potential group of respondents and how you will select them?

This project will be utilizing existing customer lists from OPTN and to identify respondents. Sample will be based on the following:

OPTN region

OPTN operates in 11 regions that serve all states and the territory of Puerto Rico. To ensure that there is a fair distribution across regions, sample will attempt to take into consideration a mix of rural and urban jurisdictions across at least 4 regions in order to take into account known underservice of OPOs and Transplant Centers in rural communities.

Underserved and Overburdened Community

A criticism of OPTN has been the degree to which it serves racial and ethnic minorities, rural populations, low-income individuals, older adults, and individuals with limited options for organ donation. To ensure that we reach respondents within the OPTN that serve these populations, sample will attempt to take into consideration the overall social vulnerability and community resilience of areas served by a respondent utilizing federal datasets, Social Vulnerability Index and Community Resilience Estimates. This will narrow outreach to a subset of each respondent type with an ideal sample of at least 30% of sample serving underserved and overburdened communities presenting high vulnerability and/or low resilience.

Roles

Where possible, stakeholder conversations will take place with individuals charged with the operations of organ facilitation, matching, procurement, transportation, and receipt rather than oversight roles.

Administration of the Instrument

1. How will you collect the information? (Check all that apply)
 Web-based or other forms of Social Media
 Telephone
 In-person **REMOTE, via Teams or Zoom, as appropriate to respondent**
 Mail
 Other, Explain
2. Will interviewers or facilitators be used? Yes, Internal Team + Contract Vendor No

Please make sure that all instruments, instructions, and scripts are submitted with the request.