

March 23, 2018

VIA ELECTRONIC SUBMISSION ONLY

Lisa Wright-Solomon
HRSA Information Collection Clearance Officer
14N39
5600 Fishers Lane
Rockville, MD, 20857

RE: Information Collection Request Title: National Survey of Organ Donation Attitudes and Practices, OMB No. 0915-0290—Reinstatement With Change

Ms. Wright-Solomon,

Following are comments from the OPTN/UNOS Executive Committee in response to HRSA's notice in the *Federal Register* Volume 83, dated Friday, February 9. Submitted by UNOS as the OPTN Contractor, these comments specifically respond to changes to questions related to minority populations and provide considerations from a patient and donor family perspective.

Background

United Network for Organ Sharing (UNOS) is a Virginia nonprofit corporation that serves as the Organ Procurement and Transplantation Network (OPTN) under contract with the Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS), and pursuant to the National Organ Transplant Act of 1984, as amended (NOTA), and associated regulations. Guided by the OPTN Final Rule, 42 C.F.R. Part 121, a major objective of the OPTN is the continued improvement of national policies to maximize the benefit of transplantation to those with end-stage organ failure. This is to be accomplished in part by defining and maintaining organ policies that are based on established medical criteria and seek to achieve the best use of donated organs.

The OPTN also provides input on proposed federal issues with potential impact on the fields of organ procurement and transplantation, such as this information collection request. The OPTN maintains a Minority Affairs Committee to consider the aspects of organ procurement, allocation and transplantation with the potential to impact minority and other vulnerable populations. The OPTN maintains the Patient Affairs Committee to provide the patient and donor family perspectives on OPTN policies and initiatives.

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OPTN Comments

The OPTN appreciates the opportunity to comment on proposed modifications to the National Survey of Organ Donation Attitudes and Practices (NSODAP), which will assess current practices with the goal of improving outreach in the community. It is important for the community to understand the perception Americans have regarding organ donation and its barriers, and be able to utilize this knowledge to make an impact on donation rates across the nation.

The OPTN supports changes made to questions regarding minority patients to be less biased and leading. Specifically, question 16A asking whether respondents agree with the statement “minority patients are less likely to receive organ transplants” (question 16A) is better focused on access to transplant than the previous version, which was more focused on discrimination. A separate question regarding the respondent’s Hispanic or Latino ethnicity (D12) is appropriate, as Latino/Hispanic is not a race and should not be included in a question focused on race (D11).

The OPTN also agrees with changes made to the overall survey to make it more accessible to the general public. The more narrow scope of the survey to focus on organ donation, as opposed to tissue donation, allows for more targeted results.

OPTN recommendations for your consideration:

Regarding question D12 on Hispanic or Latino ethnicity, the OPTN suggests including a definition of Hispanic and Latino to clarify how those terms apply, such as the one from the Office of Management and Budget (OMB) guidelines: “A person of Cuban, Mexican, Puerto Rican, South or Central America or other Spanish culture or origin regardless of race.” (Source: Statistical Policy Directive No. 15, Race and Ethnic Standards for Federal Statistics and Administrative Reporting). Additionally, adding a final choice of “Unsure,” “N/A” or “Decline to Answer” as options to multiple-choice questions in the survey provides for differences in experience and knowledge between respondents. Best survey practices recommend reformatting multiple-choice questions into response or Likert scales to better gauge the intensity of attitudes, and the OPTN recommends consideration of a similar practice in the NSODAP.

Considering the patient and general public perspective, though word choice has improved from the 2012 survey, some language could be reformatted to be less confrontational and formal. Additional common language revisions would make the survey more approachable, while the addition of a preamble explaining the goals of the survey would assist respondents in understanding the purpose and how their responses will be used. Clarification of whether questions pertain to deceased versus living donation will also help avoid confusion. In an effort to increase participation in the survey and avoid nonresponse bias, the length of the survey is commonly inversely related to the number of respondents; it is recommended that the NSODAP be shortened where possible.

Summary

We appreciate the opportunity to provide comments on the proposed modifications to the NSODAP. If you have any questions regarding our comments, or if we can provide information that would be useful as you consider the matter further, please contact us.

Sincerely,

A handwritten signature in black ink, appearing to read 'Yolanda T. Becker, M.D.', with a stylized, cursive script.

Yolanda T. Becker, M.D.

OPTN/UNOS President

Attachment

Cc: Christopher J. McLaughlin, OPTN Contracting Officer's Representative
Shannon M. Dunne, J.D., HRSA Senior Public Health Analyst
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