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From: Lisa Wright-Solomon
Information Collection Clearance Officer

Date: October 22, 2019

Request: The Health Resources and Services Administration (HRSA) requests changes to the Scientific Registry of Transplant Recipients Information Collection Effort for Potential Donors for Living Organ Donation (OMB #0906-0034)

Purpose: These non-substantive changes are necessary to improve the specificity of data collected for the Living Donor Registry and reduce administrative burden for respondents by deleting data fields that do not provide useful results.

Time Sensitivity: As soon as possible.

PROPOSED CLARIFICATION

The Department of Health and Human Services (HHS) is authorized to establish and maintain mechanisms to evaluate the long-term effects associated with living donations (42 U.S.C. §273a) and is required to submit to Congress an annual report on the long-term health effects of living donation (42 U.S.C. §273b).

The Scientific Registry of Transplant Recipients (SRTR), administered under contract with HRSA, an agency of HHS, provides analytical support to the Organ Procurement and Transplantation Network (OPTN) in the formulation and evaluation of OPTN policies and transplant system performance. HRSA modified the SRTR contract in 2016 to establish a pilot living donor registry (LDR), to be operated by the SRTR. This was done in part to help provide data to include in the annual congressional report mentioned above. Transplant centers that participate in the pilot, which was implemented in 2018, register candidates for living donation who provide informed consent to participate, with the goal of creating a living donor registry.

In July of 2019, transplant centers participating in the LDR (now called the “Living Donor Collective”) met with SRTR and HRSA staff to review data collected to date and discuss possible non-substantive changes to the data collection elements to reduce burden to respondents

and improve the quality of data collected. The group agreed on several proposed changes that will clarify the data fields and should improve the accuracy of responses. In addition, the administrative burden for respondents will be reduced since data fields that are repetitive and/or do not result in useful data will be eliminated.

Current respondents are the ten transplant centers participating in the living donor registry project.

Attachments:

Redline versions of the current living donor registry forms and living donor initial registration worksheet showing the modified data fields.