

**From:** [Erika D Lease](#)  
**To:** [HRSA Paperwork](#)  
**Subject:** [EXTERNAL] feedback - Process Data for OPTN  
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Hello,

Enclosed is my feedback regarding the proposal "Process Data for Organ Procurement and Transplantation Network."

1. Pre-Waitlist Transplant Referral Form

- a. If a referral is closed prior to seeing a patient, it is highly unlikely the transplant center will have the patient's self-identified race or ethnicity. We may not have any racial identity data (self-identified or not) with a referral. This may limit the accuracy of the data.
- b. Similarly, the transplant center may not have the patient's source of payment information if the referral is closed very early in the process (i.e. evidence of absolute contraindication).
- c. Referral Closure Reason – it is very confusing to have "evaluation started" as a reason for referral closure. We do not consider this a closure of the referral. I would prefer under "Referral Status" to have options to include "Active," "Closed," or "Proceed with Evaluation."
- d. Referral Closure Reason should include option for "Medical Complexity" as patients may be declined for a single absolute medical contraindication or multiple relative medical contraindications. It may make sense to use the same decline options as from the Pre-Waitlist Transplant Evaluation form if "Medical Complexity" is too vague.
- e. Referral Closure Reason should include option for "contraindicated infection" – for example, a history of *Burkholderia cenocepacia* or *Mycobacterium abscessus* may be considered absolute contraindications at most lung transplant centers.
- f. Referral Closure Reason should allow for multiple selections (it isn't clear to me this is planned to be allowed) – many times patients are declined for a constellation of reasons and not just a single reason. By not allowing multiple selections, it will severely limit the usability and/or accuracy of the data.

2. Pre-Waitlist Transplant Evaluation Form

- a. Selection Committee Decision/Decline Reason should include:
  - i. Significant renal disease (renal disease may be an absolute contraindication for lung transplantation)
  - ii. Significant pharyngeal, esophageal, or gastrointestinal disease (chronic aspiration, aperistalsis, or severe GER with gastroparesis may be contraindications for lung transplantation)
  - iii. "Active Infection" is not sufficient to capture the range of infectious issues that may prohibit transplantation – for example, a history of *Burkholderia cenocepacia* or *Mycobacterium abscessus* may be considered absolute contraindications at most lung transplant centers.
- b. Evaluation Closure Reason should allow for multiple selections (it isn't clear to me this

is planned to be allowed) – many times patients are declined for a constellation of reasons and not just a single reason. By not allowing multiple selections, it will severely limit the usability and/or accuracy of the data.

Thank you for the opportunity to provide feedback,  
Erika

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