

From: [Charles Bearden](#)
To: [HRSA Paperwork](#)
Subject: [EXTERNAL] Potential_SPAM:Public Comment on the HRSA OPTN Directive at the OMB for additional patient data.
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I respectfully wish to add my public comment in full support of HRSA's proposed data modifications to the Ventilated Patient Form (VPF) for OPOs

and the data collection for potential transplant recipients upon referral to a transplant center.

I write today as the longest serving (48yrs.) Organ Recovery/Transplant Coordinator in the U.S.

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and as a member of the National Academies of Sciences Engineering and Medicine Consensus Study Committee on A Fairer and More Equitable, Cost-Effective, and Transparent System of Donor Organ Procurement, Allocation, and Distribution.



These new data collection mandates are a matter of life and death for all current and future potential organ transplant recipients, especially kidney patients.

1. Information from transplant centers about when individuals are first referred to them for an organ transplant, as well as the results of their transplant evaluation and selection as a transplant candidate.
2. Information from organ procurement organizations on all ventilated patients referred to them from hospitals in their donation service area, regardless of whether such individuals progress to organ donation.

Having served as a Committee Member of the NASEM report "Realizing the Promise of Equity in the Organ Transplantation System" I can attest to the fact that we on the NASEM committee recommended both these improvements 100%. We still do. We were collectively stunned and outraged that this data was sorely absent, missing and urgently needed.

Recommendation 3. Expanding Oversight and Data Collection. pg. 7. "HHS should extend its regulatory oversight of the organ transplant system beginning, at least, the time that the patient reaches end-stage organ failure and extending beyond one year post transplant. HHS should update the OPTN contract to require the collection of disaggregated data by race and ethnicity, gender/sex, age, as well as language and the creation of new measures of inequity in the transplantation system." pg. 98 "Gaps in data present a systems Issue. It is difficult to properly assess equitable referral and evaluation for organ transplantation because a lack of national surveillance." Conclusion 4-5, 5-17. From our Statement of Task, Box S-1 pg. 3, How to more effectively acquire needed data points to enhance transplant scoring systems (e.g., through better sharing of DONOR and Recipient data between various federal agency databases.)

Too much "Burden" the poorly performing OPOs whine in their official UNOS/OPTN response via the MPSC..... NONSENSE!

From the public comment of fellow [Organize.org](https://www.organize.org) Board members and supporters.

"We also understand that such OPO opposition to patient-centric transparency is rooted in a disingenuous invoking of a supposed "reporting burden." In response, we note that – as the [House Oversight Committee](#) noted in oversight letters after investigative reporting found that OPOs were intentionally obstructing Congress's requests for such process data – CMS, via CFR § 486.328, already requires OPOs to collect and maintain all of this data, though, inexplicably, has never required OPOs to report it.

Given this, all we are discussing here is whether OPOs should have to transmit this data to the government – a process which, as has been demonstrated as entirely feasible by a collaboration between the [Massachusetts Institute of Technology \(MIT\) and six pro-transparency OPOs](#). In fact, the transfer itself took less than an hour, and has already enabled [peer-reviewed research](#) that can point to life-saving system improvements."

The peer reviewed research and published data showed why the poor performing OPOs don't want the data known. Take a look at the "peer-reviewed research" link.

They habitually blame their Donation Service Area (DSA) ethnic (anyone of color) makeup for their low consent rates and subsequent substandard performance.

The UNOS MPSC acting on behalf of HRSA and as the OPTN are opposing the new data requirements for OPOs.

This lack of oversight, when over 30 patients die everyday on the waiting list or after being removed because they are too sick to transplant, cannot be allowed to continue.

NO DATA = NO TRANSPARENCY = NO ACCOUNTABILITY = NO REFORM AND MODERNIZATION = NO IMPROVEMENT = NO EQUITY FOR PATIENTS.

Thank you for listening,

Charles Bearden PA CPTC

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