The Honorable Chiquita Brooks-LaSure
Administrator, Centers for Medicare and Medicaid Services
200 Independence Ave, SW
Washington, DC 20201

Re: Request for Information; Health and Safety Requirements for Transplant Programs, Organ Procurement Organizations, and End-Stage Renal Disease Facilities

Dear Administrator Brooks-LaSure:

As data scientists, we are writing to respond to this Request for Information about the importance of releasing all process data from organ procurement organizations (OPOs) as a way to deliver on the Executive Order On Advancing Racial Equity.

Bipartisan Congressional leaders have highlighted the urgency of accelerating OPO reform, writing: *"The COVID-19 pandemic is exacerbating the need for organs now and creating an urgent health equity issue, as communities of color are disproportionately impacted by the failures of the current organ donation system and the effects of COVID-19."*

The federally-commissioned Deceased Donor Potential Study noted that the current U.S. organ procurement system may be recovering as few as one in five potential organ donors, and peer-reviewed research shows that too often the system disproportionately fails donors - and patients - of color.

In response to the RFI's questions on (1) revisions to OPO Conditions for Coverage to reduce disparities in organ transplant; (2) metrics to reflect high performing OPOs; (3) indicators of excellence in performance for recertification purposes; (4) additional metrics to measure equity and OPO success in reducing disparities; and (5) ways to rate and assess OPO performance for purposes of recertification and competition; the answer is the same:

- **Enforce the data-driven OPO final rule as quickly as possible** so that poor performing OPOs are replaced by higher performers before 2026;
- **Collect and release all OPO process data so that CMS can have evidence of equitable treatment** of organ donors/next of kin (e.g., no inequities in response rates or response times based on race/ethnicity); and
- **Ensure that OPO metrics are not game-able** (e.g., credit only for organs that are transplanted, with no credit for zero donors or research organs);
- **Reject calls for "race-adjusted" metrics,** which would allow OPOs to provide lower service for donors of color, and runs directly counter to the Executive Order on Equity as well as calls from equity leaders including Congresswoman Ayanna Pressley, past President of the NAACP Ben Jealous, and then-Chair of the Congressional Black Caucus Karen Bass.

The United States lags international peers in publicly available OPO data (for example, see England and Australia), and that has obscured where the system fails. OPOs already collect process data; however it is not public. The answer is clear: CMS should require that all OPO process data be publicly available.

The Healthy ML Lab and Ashia Wilson's Lab at the Massachusetts Institute of Technology (MIT) is modeling what is possible, working in collaboration with seven leading OPOs from around the country and the Federation of American Scientists to publish ten years worth of de-identified process data, including data by month/race/age/sex/HIV status/hospital with time stamps.[1] As noted by bipartisan leaders at the May 4th 2021 House Oversight Committee hearing, if a segment of OPOs can voluntarily share such data, all OPOs are capable of doing so.

Open data is imperative given that OPOs operate a critical public service; that they do so at the behest of the government as monopoly contractors facing no external or competitive pressures; that their operations are paid for by taxpayers; and that their successes and failures translate to lives saved or lost of vulnerable patients on the organ waiting list, including with health equity implications.

Consider: recently released data from the Centers for Medicare and Medicaid Services showed a 10-fold difference in procurement rate of Black donors by OPOs. Open process data will show, for example, where there are differential response rates and times across the country based on donor race/ethnicity as well as other equity lenses such as rural/urban geography.

As former U.S. Chief Data Scientist DJ Patil wrote of organ donation in the Journal of the American Medical Association, "*we are not measuring the basics to enable transparency and accountability in the nation's organ donation system*." Given deep inequities within organ transplantation, opening OPO process data is a critical step to ensuring communities around the country are treated fairly, and equally given the chance to save lives through organ donation.

Yours sincerely,

Marzyeh Ghassemi
MIT, EECS.CSAIL & IMES, CIFAR Azrieli Global Scholar
Canadian CIFAR AI Chair, Vector Institute

Ashia Wilson
MIT, EECS, LIDS

Alistair Johnson
Hospital for SickKids, Toronto, Ontario

---

[1] MIMIC has similarly opened data from Beth Israel Deaconess Hospital, driving research for public benefit.

Sendhil Mullainathan
University of Chicago

Ziad Obermeyer
UC Berkeley

Tom Pollard
Massachusetts Institute of Technology, USA

Regina Barzilay
MIT, EECS, CSAIL, Jameel Clinic