May 9th 2022

Carole Johnson Administrator Health Services Resources Administration (HRSA) 5600 Fishers Lane Rockville, MD 20852 Jason Miller
Deputy Director, Management
Office of Management and Budget
725 17th St NW
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Administrator Johnson and Deputy Director Miller,

We write as the five past Chief Technology Officers for the U.S. Department of Health and Human Services (HHS) in response to the "Request for Information on Ways to Strengthen and Improve the Organ Procurement and Transplantation Network" (OPTN).

We have all worked on organ donation reform, one of the very few issues that is so bipartisan that it has been supported across administrations. This work began under the Obama-Biden Administration, including a 2016 White House Organs Summit; that these reforms persisted speaks to the uniquely bipartisan support they receive, including with ongoing support from many senior alumni of the Obama Administration. Having supported reforms for organ procurement organizations (OPOs), we write now in support of reforms to the OPTN. Given that COVID-19 is known to cause organ failure, these reforms are more urgent now than ever.

The <u>New York Times</u> wrote: "an astounding lack of accountability and oversight in the nation's creaking, monopolistic organ transplant system is allowing hundreds of thousands of potential organ donations to fall through the cracks."

Having all worked on this issue across our tenures at HHS, we agree wholeheartedly, which is why, in November 2020, we endorsed research from alumni of the United States Digital Service (USDS) cataloging severe deficiencies amongst the nation's organ donation contractors including the sole contractor for the OPTN, UNOS. The <u>research</u> highlighted "the vendor maintains an antiquated technology and limited technical acumen"; described the "technology poverty" of the status quo, and offered "recommendations to support a new approach for buying digital services" including a draft Request for Proposal (RFP).

Specifically, we encourage HRSA to:

- **Reform OPTN governance**: the OPTN and related contractor(s) should have separate boards as called for by HRSA in 2018, and reaffirmed by GAO.
- **Modernize Technology**: given high-functioning technology is critical to reducing lives lost due to unrecovered/untransplanted organs, technology should be a separate contract, as

recently <u>called for by National Academies of Science Engineering and Medicine</u> (NASEM), and the field should be opened to innovators from all sectors, ensuring a high-performing and secure system.

- Ensure data transparency: OPTN contractors should make data readily available so that the government and other stakeholders can have immediate evidence of equitable and effective treatment of donors and patients; something notably lacking from the current system (the NASEM study's principal conclusion is that the current organ donation system is "demonstrably inequitable").
- Amend the National Organ Transplantation Act (NOTA): NOTA should be amended to empower HHS to act in patients' interests through contractors and financing as HHS sees fit, rather than empowering a single contractor and locking in financing that does not serve patients over time. (See report from alumni of the United States Digital Service, including how NOTA has "erod[ed] the government's leverage" in managing the OPTN contract.)

Lastly, we note that while the Administration is likely to receive support for the status quo from the organ contractors themselves as part of an <u>ongoing special interest campaign</u>, we have all heard similar, <u>baseless claims</u>, and have not found them to be grounded in science or made in <u>good faith</u>. In fact, we note the recent <u>MedPage op ed</u> from DJ Patil, former United States Chief Data Scientist, which highlighted concerning statistics showing underperformance in organ procurement, and concluded that: "HHS should heed the call from the New York Times editorial board to "revisit the UNOS monopoly," and pursue all options for reforms to deliver a more transparent, effective, and patient-centered OPTN. Americans -- and disproportionately patients of color -- are dying unnecessarily due to OPO and UNOS failures."

As we have written before: We are strongly motivated by data that show organ donation reform can save thousands of lives every year - as well as billions of dollars to the taxpayer - and help address racial disparities in our healthcare system.

We stand ready to support the Administration in this critical health equity issue.

Sincerely,

Todd Park

HHS Chief Technology Officer, 2009-2012

United States Chief Technology Officer 2012-2014

Bryan Sivak

HHS Chief Technology Officer, 2012-2015

Bruce Greenstein

HHS Chief Technology Officer,

2017-2018

Ed Simcox

HHS Chief Technology Officer,

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Susannah Fox

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