

# Reforming Organ Donation in America

Saving 25,000 Lives per Year and \$13 Billion  
in Taxpayer Funds over Five Years

## Abstract

Each year, some 23,000 Americans receive a life-saving heart, liver, lung, or kidney transplant from deceased organ donors. Yet demand for transplants exceeds supply, with approximately 115,000 people on the waiting list.<sup>1</sup> There is potential to recover up to 28,000 more organs from deceased donors per year, saving thousands of lives and billions in taxpayer funds from the avoided costs of dialysis and increased productivity.

The gap between the number of transplants performed and this potential persists in great part due to a system of misaligned policy incentives—key players have competing agendas that are not aligned to maximize the number of organs transplanted. Transplant centers, while dedicated to patient care, adjust their level of risk aversion based on overly strict acceptance criteria and at times decline to use lifesaving organs. Organ procurement organizations (OPOs), which lead procurement of organs from deceased donors, must comply with an evaluation system that does not actually reward pursuing every organ, every time. Donor hospitals lack incentive to do more than the bare minimum of referring potential deaths to OPOs.

Fortunately, sweeping improvement doesn't require scientific innovation or development of cures; we can address these issues with policy reforms. Though some of these key players and other stakeholders have argued that the system's complexity prevents improvement, straightforward policy change has great potential for impact. Specifically, we recommend the following changes:

- The Centers for Medicare and Medicaid Services (CMS) should replace the metrics by which OPOs are evaluated, removing “perverse incentives” that discourage organ procurement and establishing a clear view of OPO performance relative to local potential.
- CMS should strengthen oversight of OPOs with smarter regulation, increased transparency and better accountability regarding performance, allowing for external audits of outcomes and referral data and creating more effective tools to address poor performance.
- The Department of Health and Human Services (HHS) should foster innovation and support increased collaboration between OPOs, hospitals, and transplant centers to maximize transplantation. Visionary practitioners also should work together to pilot new approaches.
- Policymakers and practitioners should support efforts to expand transplant centers' use of all potential organs.

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<sup>1</sup> Organ Procurement Transplantation Network, U.S. Department of Health and Human Services

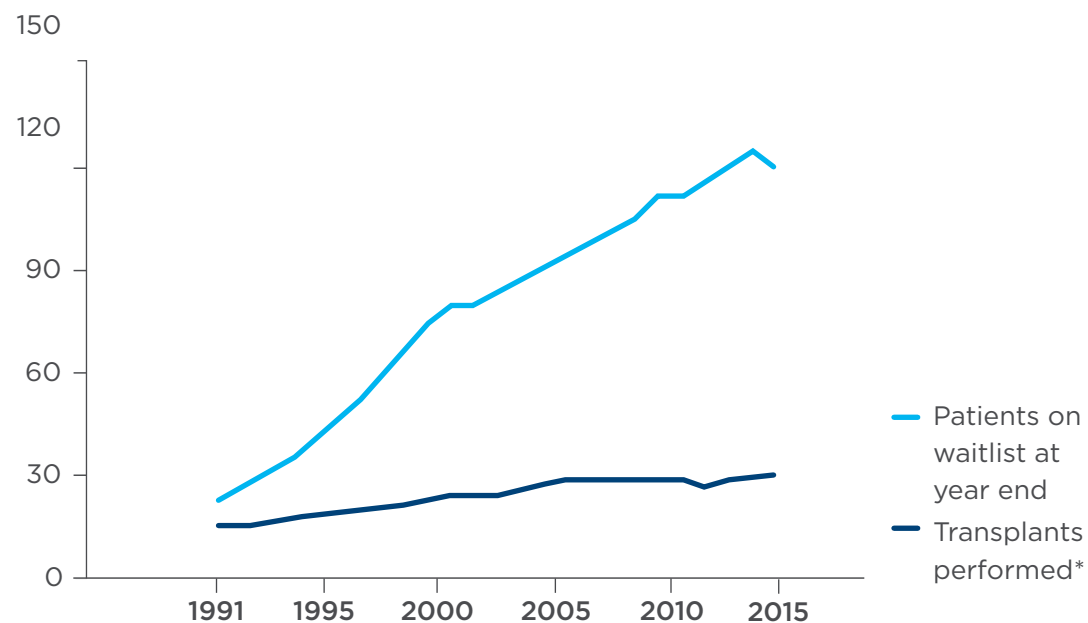
## Overview

There is an opportunity to save the lives of up to 25,000 Americans per year and \$13 billion in taxpayer funds over five years by reforming the organ donation system. Capturing this opportunity involves streamlining regulations and increasing transparency and accountability.

Each year, approximately 23,000 people receive a life-saving organ transplant from deceased donors to address heart, liver, lung, and kidney disease. However, **the demand for organ transplants far outstrips the supply of organs**—the organ waiting list includes some 115,000 people, and **6,000 to 8,000 people die each year while on the waitlist** (an average of 22 per day).<sup>2</sup>

### The demand for organ transplants far outstrips supply

Number of patients on waitlist vs. number of transplants performed per year, in thousands



\*Transplants performed includes donations from both deceased donors and living donors.

**Source:** Organ Procurement and Transplantation Network graph description of "Need continues to grow".

2 Organ Procurement Transplantation Network, U.S. Department of Health and Human Services

This gap between need and supply considerably affects the quality of life for people waiting for a transplant—often they are **unable to work and struggle with the devastating effects of ailments** such as end-stage liver disease. Their care results in huge costs to our healthcare system: Dialysis costs alone for patients awaiting a kidney transplant **totaled \$26 billion in 2014**.<sup>3</sup> Pre-empting dialysis with a transplant, however, creates a lifetime saving per patient and to the system; a unique case where the medically optimal outcome is also the most cost effective.

### Patient story

Sarah Foose was diagnosed with cystic fibrosis (CF), a debilitating lung disease, at the age of six. She was able to deal with the challenges of CF—frequent lung infections and countless hours of pulmonary therapy—until, at age 36, she decided with her doctors to go on the waitlist for a double-lung transplant. By this time, she was unable to work and began a period of sick leave from her job followed by medical leave at half pay. Through it all, she stayed focused on spending time with her six-year-old daughter, spouse, family, and friends, and getting plenty of rest. In 2016, Sarah received a double-lung transplant and is now recovering. On her “new lungs to-do list” is completing her dissertation. While Sarah received a transplant, there are 1,400 patients on the lung waitlist, and in 2017, 193 of those patients passed away while waiting.<sup>4</sup>

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3 Held et al. (2015), “A Cost-Benefit Analysis of Government Compensation of Kidney Donors”, <https://onlinelibrary.wiley.com/doi/full/10.1111/ajt.13490>

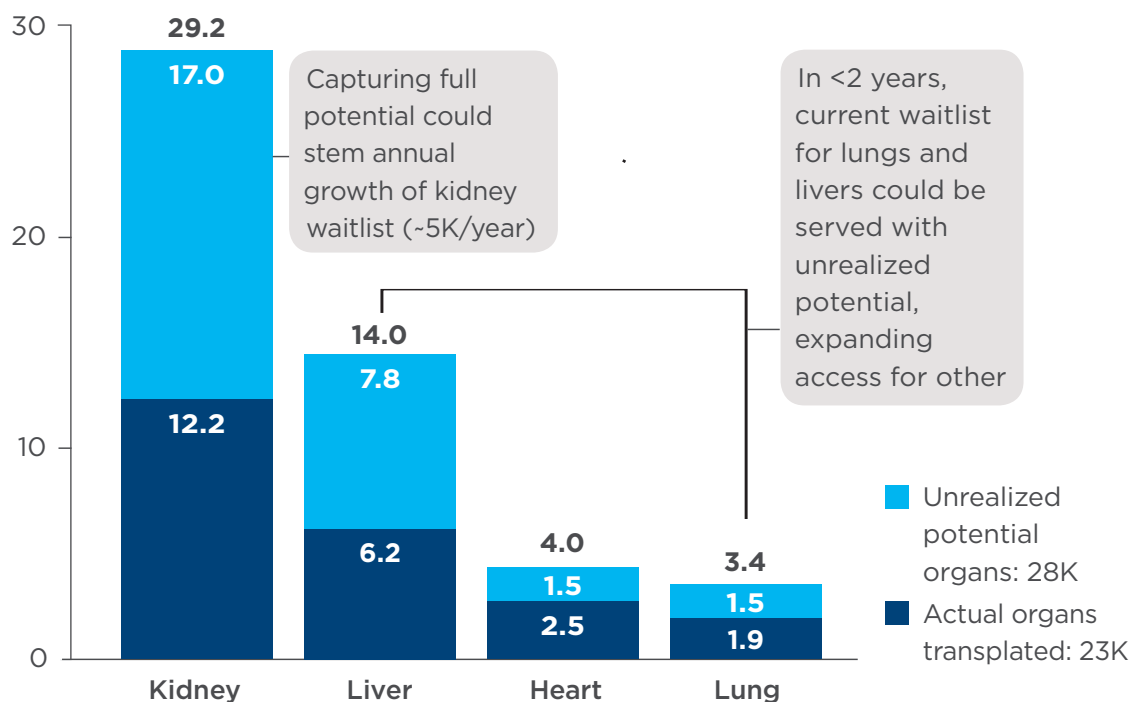
4 Interview with Sarah Foose

## The Potential

According to new analysis conducted by a research team at the University of Pennsylvania, there are approximately 28,000 **additional available organs each year from deceased donors** that do not get procured or transplanted due to breakdowns in the current system. A small number of transplant recipients receive multiple organs (~1.1 organs per recipient on average). Recovering an additional ~28,000 organs equates to ~25,000 additional lives saved.

### Unrealized potential organs varies by organ type and can improve prospects for those on the waiting list

#### Number of potential organs per year, by actual and unrealized potential (in 1000s)



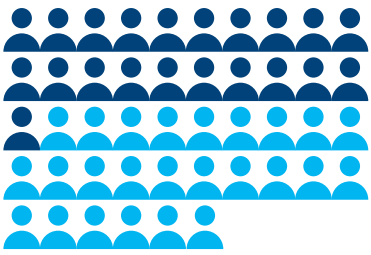
|                                 |      |      |     |     |
|---------------------------------|------|------|-----|-----|
| Patients on waitlist (K)        | 95.2 | 13.5 | 3.8 | 1.4 |
| Active patients on waitlist (K) | 65.7 | 10.6 | 3.8 | 1.4 |
| Deaths on waitlist (K)          | 3.5  | 1.1  | 0.3 | 0.2 |

**Note:** Unrealized potential organ estimates are based on analysis of 2012–2014 Agency for Healthcare Research and Quality of State Inpatient Databases data; waitlist figures are for 2018.

**Source:** University of Pennsylvania analysis; Organ Procurement and Transplantation Network.

Fixing these breakdowns could save approximately **\$13 billion for the system and taxpayers over a five-year period.**

**Reaching full potential in organs procured can improve ~25K more lives each year and save ~\$13B over five years**

|                                                                                   |                                                                                                                                                                                                                                                                                          |
|-----------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|  | <p><b>~25K more lives</b> saved or improved per year, doubling number of transplants today<sup>1</sup></p> <ul style="list-style-type: none"><li>From ~28K additional organs that could be transplanted from deceased donors (assuming an average of 1.1 organs per recipient)</li></ul> |
|  | <p><b>~\$12B more saved over five years</b> from avoided dialysis costs for Medicare<sup>2</sup></p> <ul style="list-style-type: none"><li>From ~17K additional kidney transplants from deceased donors</li></ul>                                                                        |
|  | <p><b>~\$1B increased productivity gains</b> for patients over five years</p> <ul style="list-style-type: none"><li>From ~4K additional kidney recipients and ~2K additional liver recipients returning to work<sup>3</sup></li></ul>                                                    |

-  1K patients receiving transplants today
-  1K additional patients served at full potential
-  \$1 billion

**Source:** University of Pennsylvania analysis of 2012-2014 Agency for Healthcare Research and Quality of State Inpatient Databases data; Bridgespan estimate of lives saved, cost savings, and productivity.

It is important to note that the above figures represent the “full potential” of the system, assuming 100-percent donation rates and 100-percent organ utilization. Achieving even 20-percent of this potential improvement would result in approximately 6,000 lives saved per year and \$2.6 billion in taxpayer savings over five years.

## The system today

Nationally, there are 58 OPOs tasked with managing the organ procurement and recovery process in their designated service areas (DSAs). OPOs operate essentially as government-granted monopolies, with primary responsibility for maintaining relationships with donor hospitals, obtaining next-of-kin authorization for all deceased donors, and managing the logistical transition of organs between donor hospitals and transplant centers.

Each OPO has a geographical monopoly within its DSA. All 58 OPOs are nonprofits and have their expenses compensated through a cost reimbursement contract with CMS and per-organ fees from transplant centers. Every four years, CMS evaluates OPOs, though no OPO in the last twenty years has been decertified for poor performance (despite CMS having the regulatory authority to do so). Performance of OPOs is in fact highly variable in ways that cannot be explained by local demography.

### OPO story

In 2011, the Nevada Donor Network (NDN) was categorized as a “Member Not in Good Standing” by the Organ Procurement and Transplantation Network (OPTN) because of egregiously poor performance and consequently hired a new management team. In the three years after this intervention, NDN increased the number of organs transplanted by 67%. Clearly, the strength of OPO’s management has a direct effect on the number of organs it procures.

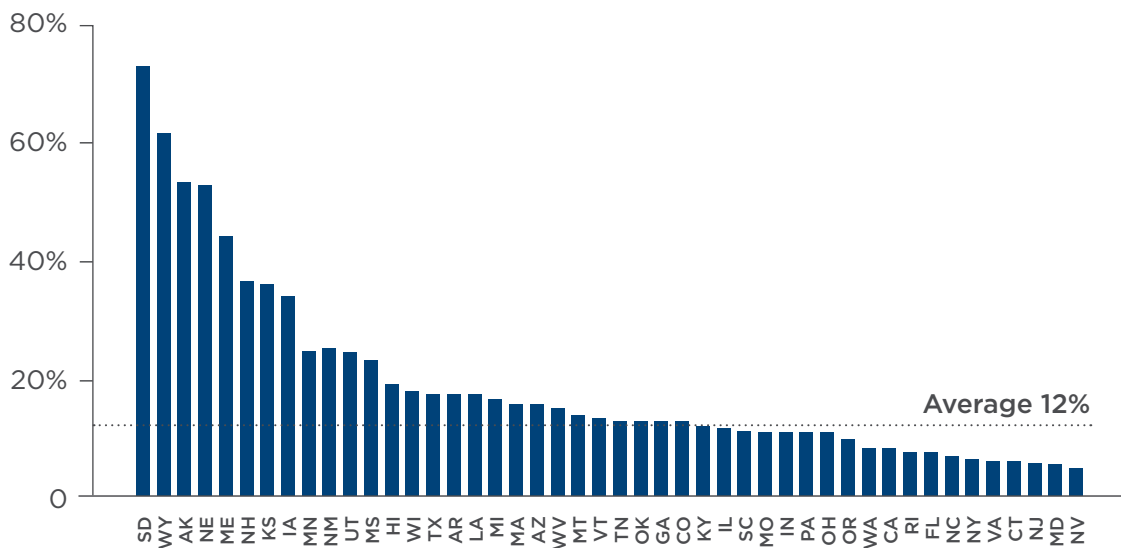
Recent debates on liver allocation across DSAs have influenced, at most, a few hundred organ transplant patients per year. It is critical to note that changes to allocation **do not meaningfully increase the total number of organs available for transplant nationally** (they only redistribute the existing supply of organs). There are, however, clear opportunities to improve overall performance of the system—**increasing the number of organs available**—that could be pursued independently of the divisive issue of allocation.

**Opportunities for improvement** span the system, from **hospitals** that identify potential donors, to the **OPOs** that shepherd donors and families through the donation process, to the **transplant centers** that eventually conduct lifesaving surgeries. These opportunities include the following:

- **Hospitals:** Critical care staff at hospitals should be on the frontlines of working with donor families, but they are often **sidelined by regulations and ineffective OPO partners**. As a result, there are discrepancies in how frequently hospitals refer in-hospital deaths to OPOs.

### Referrals from hospitals to OPOs varies across states

#### Percentage of inpatient deaths reported from hospitals to OPOs among 46 states (2009–2012)

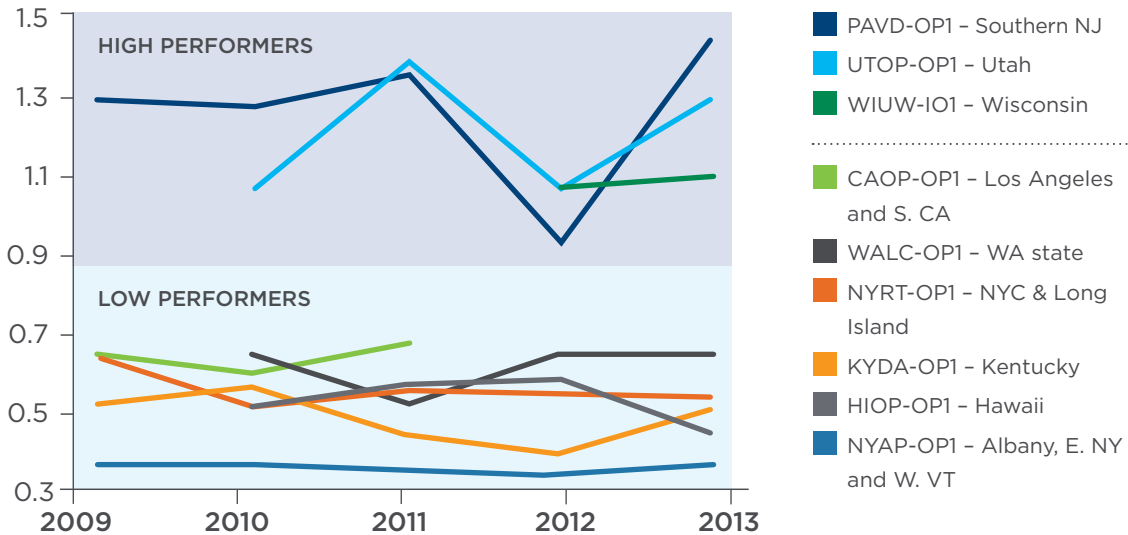


**Source:** NIS inpatient data 2009–2012 on total inpatient deaths; OPTN/UNOS data on “Reported Deaths” (defined by UNOS as “All deaths or imminent deaths (ventilated and non-ventilated) reported by a hospital to the OPO, tissue, or eye bank location within the OPO service area.”)

- **OPOs:** Each of the 58 OPOs in the United States operates as **an unchecked regional monopoly**. Performance varies across the OPO network, with **many persistent underperformers** failing to improve over the last decade. Existing **regulations need dramatic improvement to remove perverse incentives to organ procurement (e.g., OPOs are evaluated on the number of organs procured per donor, which leads to older single-organ donors being overlooked) and increase continuous performance accountability**. Another OPO performance metric, organs recovered per “eligible death”, is currently self-reported and subject to interpretation, which leaves the door open for under-reporting performance in relation to true organ availability potential.

## There are some high-performing OPOs as well as pockets of underperformance, by organs per potential donors

### Organs per potential donors per year, by OPO



**Note:** PADV's designated service area (DSA) covers eastern PA and southern NJ, but this analysis includes only southern NJ due to data availability.

**Source:** University of Pennsylvania analysis organs per potential donors in each DSA using State Inpatient Databases.

- **Transplant centers:** Current regulations focused narrowly on certain transplant center outcomes result in **significant risk aversion** while thousands of patients on the waitlist die each year due to a sub-optimized donation chain. Some viable organs are never identified by the hospital or procured by the OPO out of fear that transplant centers, **intent on complying with narrow regulations**, will not use them. One in five procured kidneys are discarded (i.e., thrown away without being used for transplant).<sup>5</sup>
  - Studies have shown that reducing transplant volumes **don't correlate with better post-transplant outcomes** for patients (e.g., lower standardized mortality ratios).<sup>6</sup>
  - **A number of transplant centers**, for example those studied in the Health Resource and Service Administration's Collaborative Improvement and Innovation Networks (ColINs) program, have successfully **maintained both high transplant volumes and high quality** of outcomes.<sup>7</sup>
  - **Advances in medicine and technology** provide transplant centers with **opportunities to innovate** to increase both number of transplants and quality.

5 Stewart et al. (2017), "Diagnosing the Decades-Long Rise in the Deceased Donor Kidney Discard Rate in the United States", Journal of Transplantation, [https://journals.lww.com/transplantjournal/Citation/2017/03000/Diagnosing\\_the\\_Decades\\_Long\\_Rise\\_in\\_the\\_Deceased.23.aspx](https://journals.lww.com/transplantjournal/Citation/2017/03000/Diagnosing_the_Decades_Long_Rise_in_the_Deceased.23.aspx)

6 Buccini et al. (2014), "Association Between Liver Transplant Center Performance Evaluations and Transplant Volume", <https://www.ncbi.nlm.nih.gov/pubmed/25307038>

7 Health Resources and Services Administration's Collaborative Improvement & Innovation Networks (ColINs) on transplantation aims to improve quality among transplant centers by identifying and spreading best practices and developing comprehensive quality monitoring indicators

**Reform is needed to save 25,000 lives** per year and approximately **\$13 billion** of taxpayer funds over the next five years:

- **Reforms to metrics:** Dramatically improve the performance of OPOs and transplant centers via streamlined regulations, increasing transparency and accountability. This can be accomplished by replacing current ineffective metrics for OPO performance with a simplified transparent metric that enables independent performance measurement.
  - For example, measuring the donation rate as: “actual donors” as a percentage of “possible donors,” with possible donors independently calculated using hospital-level administrative data, would give an objective measure of performance against potential.(See Appendix for further detail on how researchers from the University of Pennsylvania have explored such a metric). An even simpler metric could be calculated as the number of “actual donors” as a percentage of all deaths in a geographic area (or all inpatient deaths). Any of these would be a marked improvement upon the current metrics.
- **System-level reforms:** Pilot new, innovative models of organ recovery, including hospital-led procurement, and expand recourse for CMS when it identifies OPO underperformance. A powerful solution would be to allow CMS to empower donor hospitals to lead recovery efforts (similar to the world-leading Spanish Model), particularly in DSAs with underperforming OPOs.
  - Hospital-led procurement could be systematized through a standardized, third-party “designated requestor” certification process. Currently, hospital personnel can become designated requestors (enabling them to approach families about donation in place of the OPO), but the certification process is managed by the local OPO, and such requestor status is often unreasonably withheld.

## Call to action

There is significant potential for improvement in the organ donation system, with clear opportunities for reform that could lead to as many as 25,000 additional lives saved per year and \$13 billion in taxpayer savings over five years. Reforming the organ donation system offers the rare opportunity to save lives and taxpayer dollars at the same time.

Immediate opportunities for action include:

- Congress can catalyze change by calling for increased performance and transparent metrics.
- CMS should streamline existing OPO metrics and improve accountability.
- Transplant centers, OPOs, and donor hospitals can pilot new approaches to drive improvement and refine best practices.
- Patients on the waiting list and their friends and families can encourage their Congressional representatives to support reform.

## Appendix

### Comparison of OPOs by a potential new evaluation metric to assess donation rate (actual donors/potential donors)

| OPO Code (approximate geography covered) | Donation rates (actual donors/potential donors) 2012–2014 |
|------------------------------------------|-----------------------------------------------------------|
| UTOP-OP1 (Utah)                          | 56.6%                                                     |
| PADV-OP1 (Eastern PA & S. NJ)            | 56.0%                                                     |
| WIUW-IO1 (W. WI and W. MI)               | 54.2%                                                     |
| MWOB (Kansas)                            | 53.9%                                                     |
| DCTC (Washington DC area)                | 52.0%                                                     |
| NEOR-OP1 (Nebraska)                      | 51.6%                                                     |
| NVLV-OP1 (Nevada)                        | 44.4%                                                     |
| PATF-OP1 (Western PA)                    | 44.1%                                                     |
| MDPC-OP1 (Maryland)                      | 42.8%                                                     |
| CTOP (Connecticut)                       | 41.5%                                                     |
| LAOP (Louisiana)                         | 41.2%                                                     |
| WIDN-OP1 (E. Wisconsin)                  | 40.5%                                                     |
| CASD-IO1 (San Diego, CA)                 | 39.7%                                                     |
| ILIP (Chicago area, IL)                  | 39.6%                                                     |
| TXGC (Houston area, TX)                  | 39.6%                                                     |
| MIOP-OP1 (Michigan)                      | 39.3%                                                     |
| FLWC-OP1 (W. Central FL)                 | 38.2%                                                     |
| IAOP-OP1 (Iowa)                          | 37.8%                                                     |
| MOM (Missouri)                           | 37.6%                                                     |
| HIOP-OP1 (Hawaii)                        | 37.2%                                                     |
| WALC-OP1 (Washington state)              | 36.5%                                                     |
| NYWN-OP1 (Buffalo area, NY)              | 36.5%                                                     |
| NCNC-OP1 (Eastern North Carolina)        | 36.1%                                                     |
| MAOB-OP1 (New England)                   | 35.8%                                                     |

*continued*

| OPO Code (approximate geography covered) | Donation rates (actual donors/<br>potential donors) 2012–2014 |
|------------------------------------------|---------------------------------------------------------------|
| MNOP (Minnesota)                         | 35.2%                                                         |
| GALL (Georgia)                           | 35.1%                                                         |
| TXSB (Dallas area, TX)                   | 35.1%                                                         |
| NMOP-OP1 (New Mexico)                    | 34.7%                                                         |
| CORS-OP1 (Colorado)                      | 34.5%                                                         |
| VATB (Virginia)                          | 34.1%                                                         |
| CADN-OP1 (Bay Area and N. CA)            | 33.9%                                                         |
| AZOB-OP1 (Arizona)                       | 33.8%                                                         |
| INOP (Indiana)                           | 33.8%                                                         |
| AROR-OP1 (Arkansas)                      | 33.3%                                                         |
| ORUO-IO1 (Oregon)                        | 33.1%                                                         |
| FLMP-OP1 (Southern FL)                   | 32.9%                                                         |
| NYAP-OP1 (Albany area & W. VT)           | 32.9%                                                         |
| NCCM-IO1 (W. North Carolina)             | 31.8%                                                         |
| FLUF-IO1 (Northern FL)                   | 31.4%                                                         |
| OKOP (Oklahoma)                          | 31.1%                                                         |
| CAOP-OP1 (Los Angeles & S. CA)           | 30.9%                                                         |
| NYRT-OP1 (NYC & Long Island, NY)         | 30.6%                                                         |
| FLFH-IO1 (E. Central FL)                 | 30.5%                                                         |
| NJTO-OP1 (Northern NJ)                   | 30.3%                                                         |
| CAGS-OP1 (Sacramento, CA)                | 28.1%                                                         |
| NYFL-IO1 (Rochester area, NY)            | 27.0%                                                         |
| TXSA (San Antonio area, TX)              | 26.5%                                                         |
| KYDA-OP1 (Kentucky)                      | 25.2%                                                         |
| SCOP (South Carolina)                    | 24.2%                                                         |

**Source:** Analysis of Agency for Healthcare Research and Quality 2012-2014 state in-patient databases by Dr. David Goldberg, University of Pennsylvania.

## Methodology

Includes data from the state inpatient databases of 45 states, comprising 49 out of 58 total DSAs. The method to identify a “possible” deceased donor, based on prior published work, and validated against medical records data from two OPOs, used administrative data to identify in-hospital deaths among patients: 1)  $\leq 75$  years of age; 2) ventilated; 3) absence of multi-organ system failure, severe sepsis, cancers contraindicating donation; 4) died from a cause consistent with organ donation, with an in-hospital length of stay  $\leq 14$  days.

## Updates

This report was updated January 2019 to include minor clarifications:

- Updated the first paragraph on page 2 to clarify that the focus of our work was on organ transplantation from deceased donation
- Updated graphic on page 3 (headline and X-axis)
- Updated source for the bar chart on page 8

## Additional information

### University of Pennsylvania press release:

<https://www.pennmedicine.org/news/news-releases/2017/july/researchers-identify-critical-need-for-standardized-organ-donation-metrics>

### American Journal of Transplantation study:

<https://onlinelibrary.wiley.com/doi/full/10.1111/ajt.14391>

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