Organ Donation Reform Glossary of Key Terms

Terms/Acronyms	Definitions
AOPO	Association of Organ Procurement Organizations: A national organization of organ procurement organizations (OPOs). It is an OPTN member, whose president serves on the OPTN Board of Directors. It recently decided to change its status from a 501(c)(3) to a 501(c)(6) to enable it to do more government lobbying.
CCSQ	Center for Clinical Standards and Quality: Department within Centers for Medicare & Medicaid Services (CMS) that serves as the focal point for all quality, clinical, medical science issues, survey and certification, and policies for CMS' programs. See <u>Governance Map</u> .
СМ	Center for Medicare: This group within Centers for Medicare & Medicaid Services (CMS) pays organ procurement organizations (OPOs) for organ recovery through reimbursements. See <u>Governance Map</u> .
CMS	Centers for Medicare & Medicaid Services: A federal agency within the U.S. Department of Health and Human Services (HHS) that administers the nation's major healthcare programs. See <u>Governance Map</u> .
Cost Report	Medicare Cost Report: A financial document that OPOs submit to CMS to receive guaranteed reimbursement for all costs related kidney procurement. Reports have indicated that OPOs often engage in cost-shifting between kidneys and other organs in order to inappropriately maximize their Medicare reimbursement.
CSG	Clinical Standards Group: Group within Center for Clinical Standards and Quality (CCSQ) that writes the organ procurement organization (OPO) conditions for coverage. See <u>Governance Map</u> .
DBD	Donation after Brain Death: The majority of deceased organ donations take place after a physician has declared the patient to be brain dead. According to the American Academy of Neurology, brain death is the irreversible loss of clinical function of the brain, including the brain stem, and is a legal declaration of death.
DCD	Donation after Circulatory Death: Recovery of organs and or tissues from a donor whose heart has irreversibly stopped beating, previously referred to as non-heart-beating or asystolic donation. <u>See here</u> for the difference between DCD and DBD.
DH	Donor Hospitals: Any hospital that has both a ventilator and an operating room. All donor hospitals have only one organ procurement organization (OPO) that they work with, while an OPO has multiple donor hospitals they work with in their donation service area (DSA).
DonorNet®	DonorNet®: Provides organ procurement organizations with the interface to add, update, or delete donor data, execute match runs, and make organ offers. Transplant hospitals use this system to view posted donor information and record organ acceptance and refusal decisions on all organ offers.
DoT	Division of Transplantation: A group housed within the Healthcare Systems Bureau (HSB). DoT is the primary federal entity responsible for oversight of the nation's organ



	and blood stem cell transplant systems and for initiatives to increase organ and blood stem cell donations in the United States. It is the group responsible for the OPTN and SRTR. See <u>Governance Map</u> .
DSA	Donation Service Area: 58 geographic areas designated by CMS. There is one organ procurement organization (OPO) for each DSA. The 58 DSAs are organized into 11 regions.
ESRD	End-Stage Renal Disease: The complete or almost complete failure of the kidneys to function. The kidneys can no longer remove wastes, concentrate urine, and regulate many other important body functions.
Executive Order on Advancing American Kidney Health	An <u>Executive Order</u> issued by President Trump in July 2019 to address various aspects of kidney disease, including:
	 Sec. 7. Increasing Utilization of Available Organs. (a) Within 90 days of the date of this order, the Secretary shall propose a regulation to enhance the procurement and utilization of organs available through deceased donation by revising Organ Procurement Organization (OPO) rules and evaluation metrics to establish more transparent, reliable, and enforceable objective metrics for evaluating an OPO's performance.
	(b) Within 180 days of the date of this order, the Secretary shall streamline and expedite the process of kidney matching and delivery to reduce the discard rate. Removing process inefficiencies in matching and delivery that result in delayed acceptance by transplant centers will reduce the detrimental effects on organ quality of prolonged time with reduced or cut-off blood supply.
Final Rule	OPTN Final Rule: Originally proposed in 1998, the <u>Final Rule</u> was not implemented until March 2000. It changed the way organ donations were allocated in the United States, moving away from a system that favored geographic areas with large donor banks towards a system that prioritized a patient's need for organ transplant over their proximity to the donor. The Final Rule as it stands today allows for local recipients to be considered first but directs organ procurement organizations (OPOs) to offer organs nationally if a local match cannot be made, taking urgency of need into account.
	The current ruling also gives the Department of Health and Human Services (HHS) veto power over any policies created by the Organ Procurement and Transplantation Network (OPTN), administered by the United Network for Organ Sharing (UNOS), increasing the direct role of the federal government in organ donation.
HHS	U.S. Department of Health and Human Services: A cabinet-level executive branch department of the U.S. federal government with the goal of protecting the health of all Americans and providing essential human services. HHS is administered by the Secretary of Health and Human Services, who is appointed by the President with the consent of the Senate. It is where all aspects of organ donation are housed. See <u>Governance Map</u> .
Histocompatibility	Histocompatibility: The examination or testing of antigens to determine if a donor organ will "match" and be compatible with a potential recipient's system. This routine test is often called tissue-typing and helps identify the most suitable recipient for a donated organ.





HLA	Human Leukocyte Antigens: A genetically determined series of molecule markers located on human white blood cells and tissues. HLA matching is important for compatibility between organ donor and recipient.
HRSA	Health Resources and Services Administration: An agency of the U.S. Department of Health and Human Services (HHS), that is the primary federal agency for improving health care to people who are geographically isolated, economically or medi ally vulnerable. See <u>Governance Map</u> .
HSB	Healthcare Systems Bureau: An group within the Health Resources and Services Administration (HRSA) that protects public health and improves the health of individuals through programs that provide national leadership and direction in targeted areas. See <u>Governance Map</u> .
Match Run	Match Run: List that is generated when an organ donor's information is entered into the national waiting list computer system to identify potential recipients.
MPSC	Membership and Professional Standards Committee: The standing Organ Procurement and Transplantation Network (OPTN) committee charged with ensuring that OPTN members meet and stay in compliance with OPTN Criteria for Membership. They review complaints and reports of misconduct/policy violations and make recommendations to the OPTN board.
NOTA	National Organ Transplant Act: Passed by Congress in 1984, NOTA initiated the development of a national system of organ sharing and a scientific registry to collect and report transplant data. It also outlawed the sale of human organs in the United States.
NPRM	Notice of Proposed Rulemaking: Is a public notice that is issued by law when a US government agency wishes to add, remove, or change a rule or regulation as part of the rulemaking process. We use this as shorthand for the <u>2019 notice of proposed</u> rulemaking regarding changes to the OPO Conditions of Coverage, specifically around the outcome measures.
OPO	Organ Procurement Organization: There are 58 are designated OPOs across the US by the Centers for Medicare and Medicaid Services (CMS). They are each responsible for increasing the number of registered donors in their service areas and coordinating the organ donation process by evaluating potential donors, discussing donations with family members, and arranging for the surgical removal and transport of donated organs. OPOs operate within their own territory of hospitals without competition from any other organizations.
OPTN	Organ Procurement and Transplantation Network: A membership-based entity that was established through the National Organ Transplant Act (NOTA) in 1984. Its members include all U.S. transplant centers, organ procurement organizations, and histocompatibility laboratories. It is tasked with improving the effectiveness of the nation's organ procurement, donation, and transplantation system by increasing the availability of and access to donor organs for patients with end-stage organ failure.
Organ Center	UNOS Organ Center: Its primary functions are to assist in placing organs for transplantations (specifically kidneys that need to be placed nationally, and pancreata that need to be placed regionally or nationally). They also assist organ procurement organizations (OPOs) with running the donor/recipient computer matching process,



	transportation of organs and issues, and act as a resource to the transplant community regarding organ sharing policies.
QSOG	Quality and Safety Oversight Group: Group within the Center for Clinical Standards and Quality (CCSQ) that enforces organ procurement organization (OPO) conditions for coverage and implements organ donation policies.
SAC Fee	Standard Acquisition Charge: A charge calculated by OPOs based on their annual costs and number of organs procured in the previous year. It includes both indirect (e.g., management salaries, travel, office space) and direct costs (e.g., operating room time). For most organs (other than kidneys), transplant centers pay the SAC fees to OPOs and then pass those charges to Medicare and other payors. For kidneys, OPOs are reimbursed directly by Medicare.
	"Standard" is a misnomer because SAC fees vary widely by OPO and by organs, sometimes by as much as 100%.
SFC	Senate Committee on Finance: has legislative jurisdiction on matters relating to taxation, debt, customs, foreign trade, and health programs under the Social Security Act. The committee issued an <u>oversight letter in October 2020</u> , inquiring about HHS' oversight of UNOS and the OPTN.
SOG	Survey and Operations Group: Group within the Center for Clinical Standards and Quality (CCSQ) that is out in the field doing site surveys and certifications for organ procurement organizations (OPOs) and other entities.
SRTR	Scientific Registry of Transplant Recipients: Its purpose is to provide evaluations of clinical information about donors, transplant candidates and recipients, as well as patient and graft survival rates.
TIEDI®	TIEDI®: Enables transplant centers and organ procurement organizations (OPOs) to access and record donor, candidate, and recipient-specific data electronically.
TransNet™	Transnet sM : A system for creating labels for packaging and labeling organs and specimens for transplant or research. Transplant hospitals use the system to electronically check in and/or match the organ to the recipient.
ТхС	Transplant Centers: Are where patients needing a transplant are placed on a waitlist. A transplant program is defined as a component within a transplant hospital that provides transplantation of a particular type of organ to include; heart, lung, liver, kidney, pancreas or intestine.
UNOS	United Network for Organ Sharing: A private, non-profit organization based in Richmond, Virginia, that has been the only contractor for the Organ Procurement and Transplantation Network (OPTN).
Wait List / Waiting List	Wait List: A national database maintained by the OPTN of all patients waiting for an organ transplant. It is made up of sublists of patients waiting for specific organs.

