Organ Donation and Transplantation Dashboard

Frequently Asked Questions (FAQs)

July 2024

1. **What is the purpose of the dashboard?**

   HRSA created the dashboard to:

   - Enhance transparency around the organ donation, procurement, and transplantation system.
   - Provide the public with accessible information on the organ donation, procurement, and transplantation system.
   - Identify opportunities to assess and improve equitable access to organ transplantation.

   To accompany the new dashboard, HRSA also released the raw data that the dashboard displays in the form of a Public Use File (PUF). The PUF enables the public to conduct their own research activities with high quality data while maintaining the confidentiality of each individual.

2. **Why did HRSA develop the dashboard?**

   HRSA developed the dashboard (https://data.hrsa.gov/topics/health-systems/organ-donation) to improve accessibility and increase the transparency of information about the national organ donation, procurement, and transplantation system for the public.

   HRSA hopes that the public, and those with a specific interest in organ transplantation, will find the enhanced transparency of these data helpful. These data may create opportunities to improve equitable access to organ transplantation and enhance data-driven program monitoring.

   HRSA views this dashboard as first step toward improved data transparency and data driven performance improvement. HRSA will regularly update the dashboard and engage the community to inform development of future iterations of or additional dashboards.

3. **Does the dashboard or data have limitations?**

   HRSA developed the dashboard to present clear and straightforward information, and as such, they largely present information such as counts and percentages. However, it is important to note that assessing the performance of the organ donation, procurement, and transplantation system is complex and the data counts and percentages presented may not capture all of this complexity. In many cases, additional data and/or information may be necessary to more fully understand and address key policy issues.

   Working with data to understand complex health organizations or systems, such as those involved with organ donation, procurement, and transplantation, can be challenging and there

are data limitations. Two key limitations of the dashboard are that data is not currently available to HRSA in real time, and the dashboard only presents raw data that has not been statistically adjusted to account for risk factors (*risk adjustment* - https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/Downloads/Risk-Adjustment.pdf).

Another limitation is that the individuals reflected in the dataset may have certain characteristics that can change during the year. For example, individuals might change their type of health insurance in the middle of a given year. In this situation, the dashboard reflects characteristics for individuals (such as health insurance type) as of December 31 of each year.

Additionally, in order to maintain the privacy of the individuals whose information is reflected in these pooled data sets, HRSA had to suppress some of the information in the dashboard and in the accompanying Public Use File (PUF). As such, there may be more detail needed by users of this site than what the information in the PUF can provide. Further data regarding the Organ Procurement and Transplantation Network (OPTN) is available on the OPTN website at https://optn.transplant.hrsa.gov/.   There are other data sources supported by HRSA and Centers for Medicare and Medicaid Services (CMS) that also analyze organ use data to measure the performance of organ procurement organizations (OPOs) and transplant centers and may have additional information that could be useful. These websites include: https://www.srtr.org/ and https://qcor.cms.gov/main.jsp.

Of note, data presented within individual components of the dashboard are often collected independently from the data in other components. In addition, the response rates for certain data items that are collected directly from individuals may vary. As such, the sum totals in various dashboard components can be different, even on a single dashboard tab. As one example, on the *Organ Donors Demographics* dashboard tab, the total of female and male respondents in the *Organ Donors by Sex* dashboard component may (or may not) differ from the total in the *Organ Donors by Race/Ethnicity* component.

4. Why were certain data 'suppressed' on the dashboard?

Data is suppressed to protect the confidentiality of individuals in the dataset. The data contains information on individuals that sometimes fit into a very small subset that could potentially be extrapolated to determine the individual's identity if these suppression rules and safeguards had not been put in place. HRSA applied the following suppression rules to the dashboard and accompanying public use data file:

- HRSA lists all counts less than 16 as "suppressed" with two exceptions – counts for the "Not Reported" category and any counts of zero. In addition, when the (non-zero) count in a given category is less than 16, HRSA suppresses both it and the category with the second lowest count. This is to avoid possible back calculation of the category with the lowest count from the total (i.e., if you know that there is a total count of 100 and one count value is suppressed, you can back calculate the suppressed value by subtracting the remaining counts from the 100 total).

- In the PUF, HRSA lists all percentages where the denominator is less than 11 as "suppressed."

- HRSA displays suppressed categories in the dashboard charts as empty categories, without any number.

5. Why is the information in the dashboard different than similar information I have seen elsewhere?

Many government agencies and non-governmental entities provide data related to various aspects of organ donation, procurement, and transplantation. Information and data presented on these websites can vary in important ways. For example, different calculations, risk adjustments, data suppression rules, and means for handling missing data may be applied across the various data and information sources available online. These varying approaches to collecting, analyzing, and presenting data may result in source-specific variations. HRSA has made every effort to be transparent about the agency's approach to present raw data in the dashboard.

6. How should I interpret the information in the dashboard?

Users of this information should use caution when interpreting these metrics without considering the full context for and potential limitations of the data.

7. Who are the donors included in the dashboard?

Donors are individuals who give the gift of organ donation to those in need, and they may donate one or more organs. These data identify the numbers of both living and deceased donors who have donated organs with the intent of the organ(s) being transplanted into people needing them.

8. What is the difference between a transplant waitlist candidate and a registration?

A waitlist candidate is an individual person on the organ transplant waiting list. A candidate may have more than one registration if they are waitlisted (or registered) for one or more organs at multiple transplant programs. Therefore, the number of registrations is often larger than the number of waitlist candidates.

9. What organs are included in this dashboard and the accompanying downloadable data file (PUF)?

The dashboard and accompanying Public Use File (PUF) contain information on many different types of organs procured by OPOs for the purposes of donation. These include heart, kidney, liver, lung, pancreas, intestine, and vascularized composite allografts. However, due to the low number of organ donations and transplantations in some categories, HRSA suppresses data on certain organs to protect the confidentiality of individuals in the dataset. As HRSA works to build new, additional features into the dashboard, the agency will work to find ways to present these data while maintaining protection of Personally Identifiable Information (PII). Avoiding PII disclosure was an important priority for HRSA when developing the dashboard and accompanying PUF.

10. **Why is health insurance status only reported for living (and not deceased) donors?**

    Health insurance status is only known for living organ donors.

11. **How are deceased donor organ transplant rates defined?**

    The data presented in the dashboard and accompanying Public Use File (PUF) identify the numbers of organs procured from deceased donors with the intent of eventually transplanting them into people needing organs. However, the path from organ procurement to transplantation is complex, and there are many details that affect whether or not a donor organ is eventually transplanted.

    The organ transplantation rate is defined by the following formula:

$$\frac{Number\ of\ deceased\ donor\ organs\ transplanted}{Number\ of\ deceased\ donor\ organs\ recovered}$$

    It is very important to note when reviewing these rates that the procurement and transplantation process is different for each organ, and these differences typically lead to higher transplantation rates for donated hearts, lungs, and livers relative to other organs. In addition, events in the organ procurement process can affect the use of the organ, as can clinical issues affecting the patients who are identified to receive the organ. Non-use of an organ is therefore not necessarily a reflection of a failure of the nation's organ transplantation system. Websites supported by HRSA and the Centers for Medicare and Medicaid Services (CMS) analyze these organ use data to measure the performance of organ procurement organizations and transplant centers. These websites include (https://www.srtr.org/, https://optn.transplant.hrsa.gov/, and https://qcor.cms.gov/main.jsp). If a donor organ is unable to be transplanted, efforts are made to preserve the organ for medical research. HRSA recognizes that every deceased donor organ is a gift of life and prioritizes activities to increase use of these precious gifts.

12. **Why am I unable to filter the dashboard data by racial/ethnic groups, sex, or age groups?**

    The population of donors in various subpopulations – as defined by race, ethnicity, sex, or age group – is inherently smaller than the whole donor population. Some donor subpopulations are very small in number. As a result, the ability to filter the data by these subpopulations has an increased potential risk for disclosure of Personally Identifiable Information (PII). Avoiding PII disclosure was an important priority for HRSA when developing the dashboard and accompanying PUF. As HRSA works to build new, additional features into the dashboard, the agency will work to find ways to present more refined information to the public on donor subpopulations as possible, while maintaining protection of PII.

13. **Where can I find the Scientific Registry of Transplant Recipients (SRTR) official listing of OPO service areas (donor service areas)?**

    This information is available on the Scientific Registry of Transplant Recipients (SRTR) webpage here: https://www.srtr.org/reports/opo-specific-reports/.

14. **Where can I find more detailed data or additional information about organ donors?**

Other websites supported by HRSA and the Centers for Medicare and Medicaid Services (CMS) provide data and information on organ donors, as well as analyze organ use data in order to measure the performance of organ procurement organizations and transplant centers. These websites may have additional information that could be useful. These websites include the Scientific Registry of Transplant Recipients (SRTR) webpage (https://www.srtr.org/), the Organ Procurement and Transplantation Network (OPTN) webpage (https://optn.transplant.hrsa.gov/), and the Survey and Certification (S&C) Quality, Certification and Oversight Reports (QCOR) webpage (https://qcor.cms.gov/main.jsp).

15. **Where can I find additional data to use with the downloadable data included with this dashboard?**

The HRSA Data Warehouse has a subpage called Related Data Sites (https://data.hrsa.gov/related-sites) that lists many potentially helpful data sets from inside and outside of HRSA that may be helpful to examine while using this dashboard and its accompanying Public Use File (PUF).

16. **How can I provide feedback on this dashboard including recommendations for additional data elements that would be useful to my work?**

To ask questions or provide feedback on the dashboard and/or PUF, including recommendations for additional data elements or dashboards, please email HRSA's Division of Transplantation at AskDoT@HRSA.gov.

17. **Why are the graft and patient survival percentages different than what I see in the SRTR data information?**

HRSA is providing only the raw numbers/data related to graft and patient survival. For additional details on the calculations used by the SRTR in performance assessment, please see the SRTR website (https://www.srtr.org/).

18. **Why would the status of graft or patient survival be "unknown" or "blank"?**

HRSA is presenting specific, point-in-time data related to graft and patient survival. As such, unknown status could be due to numerous factors, including the possibility that the organ transplant center is no longer tracking the patient or a particular time point is not yet reportable for an individual patient (e.g., when the point in time data is captured for this dashboard, some number of patients will not have met the 30-day or 1-year survival reporting time period). Value can also show as blank due to data suppression rules incorporated by HRSA.

19. **Is patient survival just a function of the transplantation success, or are there other factors that influence patient survival rates on the dashboard?**

Patient survival is not always due to failures in the transplantation surgery. For example, some patients die due to other causes, including accidental death, death related to other disease, or illness, or not taking required medications consistently with doctor's recommendations.

20. **How does the dashboard handle mergers, closures, name changes, inactivations, and other organization-level events for entities involved with organ transplantation?**

> Entries for Organ Procurement Organizations and Organ Transplant Centers in the Dashboard and the associated data files will reflect their names/statuses as of the data refresh date listed on the dashboard webpage. As such, organizations that have previously changed their names or that were merged into other organizations will only be reflected with their current status. Some Organ Transplant Centers may be listed as "INACTIVE". These INACTIVE OTC sites were formerly active in organ transplantation and remain listed because they may have data available during the timeframe shown in the Dashboard. However, INACTIVE status in the dashboard is determined on the date that the data was pulled and is potentially subject to change.