Methodology

Summary

The Washington Post analyzed public data to attempt to gauge the potential number of organs that could be recovered for transplantation in the United States. The Post's approach was based on previously published peer-reviewed studies on the subject. The Post replicated the previous research. It updated the research by performing analysis on more recent data than the published studies. It expanded the research by applying the findings both nationally and locally. It also added further adjustments for the number of potential organs based on donor characteristics. The study found 75,500 as the best estimate of potential organs in 2016. The findings indicated that less than half of the potential organs are being collected, a deadly shortfall given growing waiting lists for life-saving organs and people dying daily while they wait. A breakout of organ collection and potential by age ranges and types of death revealed that the shortfalls are happening with older potential donors and donors who suffer cardiac death rather than brain death. Additional findings show a wide deviation in the level of performance among organ procurement organizations (OPOs) geographically around the country, ranging from recovering three-quarters of the estimated potential organs to less than one-quarter of the estimated potential organs.

Background

Researchers have tried to estimate the potential number of transplant organs for decades. One of the largest studies was funded by the U.S. Health Resources and Services Administration. The study is available on the Organ Procurement and Transplant Network (OPTN) website. [link] A shortened version was published in 2016 in the American Journal of Transplantation, "The OPTN Deceased Donor Potential Study: Implications for Policy and Practice."[link] The Post also obtained from United Network for Organ Sharing (UNOS) the appendices that are not published online. The study started by assessing the characteristics of the universe of deceased organ donors. Using those characteristics, the study had two teams create estimates of potential deaths. The first team, called "Interested Parties Group," used Agency for Healthcare Research and Quality (AHRQ) National Inpatient Sample data from hospitals.[link] The second team, called "Organ Procurement Organization Committee," used mortality data from the Centers for Disease Control and Prevention National Center for Health Statistics based on all death certificates in the United States. [link] The strength of the National Inpatient Sample is that it includes the patient's medical record of diagnoses and procedures. The National Inpatient Sample's shortcoming is that it is only a sample and may be insufficient for estimates in single years or small geographies. The strength of the death certificate data is that it includes every known death in the country. The shortcoming is that it does not have the full medical record, only a list of the causes that contributed to death.

Both approaches started by identifying appropriate cases by age and place of death. Only deaths of people age 75 or younger are considered. Only deaths of hospital patients (inpatient, not emergency department) are considered. Both then used lists of diagnoses for medical criteria. The first list of diagnoses would exclude people from being suitable for organ donation, such as metastasized cancer or sepsis from infections. Any death from National Inpatient Sample data or death certificates that had any one of the exclusionary diagnoses was removed from the pool of potential donors. The second list of diagnoses make a person more likely to be a viable donor, such as death by brain injury or suffocation. To be considered a potential donor, a candidate had to have none of the disqualifying conditions and at

least one of the inclusionary conditions. The lists for the two teams were not identical because the first team used International Classification of Diseases, Ninth Revision (ICD-9) codes to match the National Inpatient Sample data, and the second team used International Statistical Classification of Diseases and Related Health Problems, 10th revision (ICD-10) codes to match the CDC death certificate data. The exclusion and inclusion codes are in accompanying tables on this report.

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The next important issue was being on a ventilator. To be a donor, a dying person must be on a ventilator before death to maintain oxygen flow to the organs. The team using the National Inpatient Sample required any potential donor to have medical procedure codes indicating use of a ventilator before death to maintain oxygen for organs. The second team's source records -- death certificates -- do not include information on whether or not a ventilator was used. To adjust for ventilator usage in the death-certificate study, the National Inpatient Sample data was analyzed to find rates of ventilator use by cause of death and by year. Those rates were then applied as a proportional reduction to the number of potential donors in the study using death certificate data. In the final steps, the first team also removed potential donors by length of stay in the hospital and an index of co-morbidity codes to remove candidates who were most likely to be too ill to donate organs.

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Both teams used data through 2010. The two teams found very similar numbers for potential donors, roughly 37,000 annually. That figure reflects an estimate of the number of deaths of people (1) in the appropriate age range, (2) dying as a hospital inpatient, (3) lacking any identified disqualifying conditions, (4) including cause of death likely to make donation possible who had (5) breathing maintained on a ventilator.

As part of the study, both teams used the trends up through 2010 to attempt to project the future potential of deceased donors. Fluctuations in the data up to 2010 made trend lines into the future problematic. It was challenging to estimate whether changes in ventilator rates would continue or flatten, a key factor in adjusting the estimate. Neither foresaw changes like the opioid crisis changing patterns of death in the country.

The published study contained discussion that indicated that the estimate was likely high. For instance, a patient who dies can have conditions that would preclude donation, but if the conditions are not considered a cause of death, it will not be listed on the death certificate. Doctors, coroners, medical examiners and funeral directors who fill out death certificates may be inconsistent in how inclusive they are of peripheral causes of death. Sepsis is an example of a condition that would preclude donation but may not be listed on a death certificate. After publication, the study was also criticized for overstating the likely donation potential of patients who expire from heart death rather than brain death.

In 2017, a paper titled "Changing Metrics of Organ Procurement Organization Performance in Order to Increase Organ Donation Rates in the United States" published in the American Journal of Transplantation [link] improved on the estimates. Authors included experts from the University of Pennsylvania, former acting Surgeon General Kenneth P. Moritsugu, and Howard Nathan, president and chief executive officer of Gift of Life, the OPO in Philadelphia. That study included a review of patient files to determine likelihood of suitability for organ donation. It then applied those findings in a replication of the Deceased Donor Potential Study. It replicated the study with the National Inpatient Sample data for 2008 through 2012. It used the same age cutoff, exclusion and inclusion codes, and ventilator adjustment. To adjust for the prior overestimation of donor viability for patients who die by cardiac death, it used a study of patient case-file records to estimate that 40 percent of patients

identified as potential donors by the filters die by brain death and 60 percent die by cardiac death. In the latest study, the brain death cases that fit all filters were included as the potential donors. All cases of cardiac death for people age 65 and older were removed from the potential donors since organs from people who die a cardiac death at that age are very unlikely to be suitable for transplant. Of the cardiac-death patients up to age 64, the potential donor estimate was reduced by one-third to account for the fact that cardiac deaths sometimes happen too slowly to allow organ collection. The remaining two-thirds of that group were included as potential donors. The study then validated the findings against patient-level study from two OPOs. The study found an estimated 24,000 potential donor deaths per year for 2008-2012. That estimate was a reduction of 13,000 donors, or 35 percent, from the prior Deceased Donor Potential Study result.

Washington Post Replication

The Post replicated the work of the Deceased Donor Potential Study team that performed the study on the CDC death certificate data. The Post used public data available for download. [link] The death data does not contain personally identifiable information. The most recent data was for 2016. The "multiple mortality" data includes up to 20 "index codes" for each deceased person. Each index code is a contributing cause of death.

The Post excluded all deaths above age 75, which is the 99th percentile of donor age according to research on organ donors. The Post restricted donors to hospital inpatients (not emergency room). The Post followed the list of exclusionary codes as listed in appendix D of the original study. There were 303 exclusion codes for conditions such as malignant metastasized cancer or sepsis or other contagious conditions. Any death that had at least one exclusionary code among its index codes was excluded. The Post used the list of inclusionary codes as listed in appendix E or the original study. There were 179 inclusion codes for conditions such as head wounds or suffocation.

The death-certificate data does not have any indication of ventilator use before death to keep organs supplied with sufficient oxygen. As with the original Deceased Donor Potential Study team using death certificate data, the Post adopted the findings of the team that used the National Inpatient Study for ventilator rates. The Post applied the annual average rates as reflected in the study, ranging from 65 percent in 2003 up to 76 percent in 2010. The Post used the 76 percent rate in subsequent years. After the cases were (1) filtered for age, (2) inpatient status, (3) exclusionary codes and (4) inclusionary codes, the final number was multiplied by the (5) ventilator percent to produce the final estimated number of donors.

The Post's study successfully replicated the earlier study. The Post's numbers did not match the published results for 2000, 2001 and 2002.The discrepancy appeared to be in the age categorization of the cases in those years. The first age filter applied yielded different numbers than the published results. No cause for this discrepancy was discovered. Results from 2003 forward were used. For the remaining years, the Post estimate was within 0.06% of the original study. For instance, the original estimate for 2009 was 35,615 and The Post got 35,619 (+0.01%). For 2010, the original study got 37,258. The Post study got 35,271 (+0.03%). Results are listed in Table 1 below. The small variance may be explained by constant updates that are made to the data by the CDC as additional information on particular cases

arises. Only a small number of cases are changed, which may explain the very small variance from the prior study.

The Post then updated the estimates by applying the modifications introduced in the 2017 study. The Post applied the adjustments for brain death and cardiac death to the original replication of the Deceased Donor Potential Study using the death certificate data. Making those adjustments, The Post found an average of 24,300 deaths per year over 2008-2012, very similar to the 2017 study findings. A strength of the original Deceased Donor Potential Study was that analysis of the National Inpatient Sample yielded a very similar estimate to the analysis of the CDC death certificate data. Similarly, The Post study with death certificate data paralleled the 2017 published study that had been performed with the National Inpatient Sample data.

Post National Estimates

The Post study with death certificate data applied the brain-death/cardiac-death adjustment up through 2016, finding an estimate of more than 27,000 potential deaths. The full numbers are in Table 2 below.

To estimate the number of organs, The Post applied a further adjustment. The standard measurement for organ yield from a donor is three organs per case. But organ yield differs from cases of brain death and cardiac death. The most recent data published by OPTN shows an average of 3.3 organs per donor for brain death cases and 1.9 organs per donor for cardiac death cases. The Post donor estimate contains specific estimates of cardiac and brain death. The number of cardiac deaths was multiplied by 1.9 and the number of brain deaths was multiplied by 3.3. That calculation yielded a national estimated organ potential of 75,500. Full figures are listed below in Table 3.

Compared to the estimated potential of 27,000 donors and 75,500 organs, the nation had 9,971 actual donors and 30,497 transplanted organs from deceased donors in 2016. The actual yield is less than half of the estimated potential.

Local performance metric

For years, measurement of performance by local OPOs has been done using the number of eligible donors identified by the group. Studies such as “How Inaccurate Metrics Hide the True Potential for Organ Donation in the United States,” published this year in the journal Progress in Transplantation [link] showed that “eligible” deaths are a subjective value that can potentially be manipulated by organizations to adjust their performance ratings. Various writings, for example link, have called for a more objective universe against which to measure organ procurement as a metric. The Post tabulated the potential deaths in each OPO service area to generate a less subjective measure.

The Scientific Registry of Transplant Recipients publishes the counties for which each OPO is responsible. [link] The Post used that published list of counties to assign every death certificate in the country to the appropriate OPO donation service area. There are a handful of counties where organizations share responsibilities, with one OPO working at particular hospitals and another OPO at different hospitals. Those are mostly in urban areas. For areas in which two OPOs share a county, the deaths were included in the designated service area (DSA) for each group. Therefore, the number of deaths does not add up to the national total. There are 58 OPOs, including one that covers Puerto Rico. The Post used the 57 OPOs

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that cover the 50 states and the District of Columbia, which matches the CDC death certificate data. The Post did not analyze data for Puerto Rico in the national estimates and did not analyze deaths in Puerto Rico to gauge local performance.

The downloadable CDC multiple-cause-of-death death certificate data does not have any geography. That data could not be used to assign deaths to a DSA. The CDC's online mortality data tabulator at wonder.cdc.gov does allow filtering data by county. The online tabulator allowed filtering by age and for deaths only of hospital inpatients.

The Post used the "multiple cause of death" version of the online tabulator to apply the inclusionary and exclusionary codes. (There is a "compressed mortality" that uses only the primary cause of death.) A multi-step process was used with the tabulator to get a count of appropriate deaths in each donor service area for each year. All steps included filtering for no older than 75 and inpatient status at time of death. The first step was to get a count by year using the full list of inclusionary codes. The tabulator will include any death that has at least one of the codes. Outputs were exported. The second step used the same list of inclusionary codes, but a second box in the tabulator allows a second set of diagnoses. The exclusion codes were put there. The tabulator identifies each case that has at least one match in the first set (the inclusion codes) and at least one match in the second set of codes (the exclusion codes). Those cases are not suitable for donation. Those results were exported. The base number for each donor service area was created by subtracting the second set from the first set. To make the adjustments for cardiac and brain death based on deaths of people up to age 64 and from age 65 to 75, the same two steps were run again for patients only age 65 to 75. The second pair of results were exported. Taken together, the four numbers were used to find the number of potential donors up to age 64 and the group up to age 75 to allow calculation of the potential number of cardiac death and brain death cases.

The Post then applied the ventilator rate on a year-by-year bases through 2010, and the 2010 rate of 76 percent for subsequent years through 2016, the latest data available in CDC Wonder.

Data shortcomings

One defect that was noted was that Georgia death certificate records are incomplete for 2008 and 2009 with regard to location of patient death, listing virtually no cases of inpatient death. That data defect caused a dip in the estimates in the prior Deceased Donor Potential Study, but the cause was not described in that study. The lack of inpatient deaths for those years in Georgia renders the estimate of potential for those years incomplete and metrics for measurement of performance in Georgia in those years invalid.

As discussed above, the lack of actual ventilator data in the death certificate data is a shortcoming. Since ventilator rates were rising for the period from the early 2000s through 2010, the use of the 2010 rate of 76 percent is likely to represent an understatement of the ventilator rate, which could be lowering the estimate of potential.

Also, as discussed above, the description of OPO donor service areas lists some counties as shared between multiple OPOs. In those cases, some hospitals work with one OPO while other hospitals work with another. So some counties are assigned to two OPOs. Any county listed for multiple OPOs will count all deaths in that county in each OPO. That leads to double-counting of deaths. The DSA totals are higher than the national totals. Since the OPO is not dealing with every hospital in the affected counties,

the death count is an overstatement of potential. The OPO that may be most affected is Connecticut, which shares counties with OPOs in New York and Massachusetts. Most of the other shared areas are less significant.

The study "Changing Metrics of Organ Procurement Organization Performance in Order to Increase Organ Donation Rates in the United States" combined data estimates with patient-record review at two OPOs to measure accuracy of the data estimate. The Post was not able to conduct similar validation. OPOs who reviewed the findings said that potential from cardiac death is likely to be overestimated, in part because a person must die soon after the ventilator is removed for the organs to be in usable condition, and estimation of the time to death is not precise. Some OPOs are creating technology to improve estimates in those circumstances. OPOs representatives also said that The Post's findings may be high because many prospective donors have medical conditions that are undiscovered until a detailed examination is performed prior to donation.

Resulting Metrics

With input from OPOs, The Post created two primary metrics for measuring performance. The metrics used the combination of data on actual organs collected or transplanted from OPTN/UNOS, and the Post's estimates of deceased donor potential. The first was the quotient of actual deceased donors and estimated potential donors, the donor share. The second was the quotient of actual organs recovered and estimated potential organs, the organ share. Other potential metrics were calculated and examined, such as the quotient of organs recovered and potential estimated donors, and the quotient of organs transplanted and estimated potential donors. Sub-rates of the primary metrics were also created specifically for deaths by cardiac death (DCD) and deaths by brain death (DBD), using the organs collected from those types of deceased donors and the corresponding estimated potential. Sub-rates were also created for age ranges, using the organs collected from those age ranges and the estimated potential in those age ranges.

For the donor share, the number of donors was divided by the estimated potential donors and then multiplied by 100, so the value is donors per 100 estimated potential donors. For organ share, the number of organs collected was divided by the estimated potential organs then multiplied by 100 so it is organs per 100 potential organs. Potential organs were estimated by the breakdown of estimated DCD and DBD donors. The latest average yield for DBD donors is 3.3 organs. The latest average yield for DCD donors is 1.9 organs. The estimated deaths in each category was multiplied by the average yield in that category and the sum of those values was the estimated number of potential organs. The Post used this organ share metric for evaluating OPO performance.

The metrics were tested for correlation to OPO size. None of the metrics showed a correlation with the sheer number of deaths within the OPO or the geographic size. They metrics were also tested against the share of donors who are DCD, and no correlation was found. The proposed metrics are also not correlated to the traditional metrics of conversion percent or collaborative conversion percent. The metrics did correlate with a raw calculation of donors per deaths in a OPO donor service area (DSA). That has been used previously as a crude measure of OPO performance. We feel the refinement of

identifying the location of death, cause of death and age of death in a service area provides a better measure of performance.

While the total number of deaths up to age 75 in an area is correlated to the Post's estimate of potential donors, there is variation in that relationship. At the low range, about five percent of all deaths up to age 75 met the potential donor criteria in DSAs around New York and New Jersey. The high end was 10 percent of deaths meeting donor criteria in Colorado, Hawaii and Utah. As mentioned above, Georgia's rate for 2008-2009 cannot be measured because of failure to note hospital inpatient deaths in the state death records in those years. Georgia's state-level coding defect in death certificates could be an indicator of other undetected regional differences in the data that underlies this analysis. For instance, New York death certificates may be coded in a way that highlights conditions that preclude donation and/or ignores conditions that would indicate someone is a potential donor. The potentially deflated rate of potential donors lowers the denominator of the metrics, which could raise the metric rating for that region. Three of the four OPOs in New York, however, fall in the lower range of the metrics. At the other end, places with high proportion of the deaths classified as potential donors have a higher denominator that could lower their metric score. Hawaii, Colorado and southwest Ohio have the pattern of a relatively high denominator and overall low metric scores. But Utah, eastern Wisconsin, western North Carolina and Maryland have relatively high denominators and high overall metric scores. So the variation in the share of deaths that meet the criteria to be donors is an important factor to consider for future improvement in the data, but not a deciding factor in the metric measurement.

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To avoid inconsistencies caused by one-year variations in data, comparison of OPO performance was done with metric scores averaged across complete year data for the last three years available, 2014-2016. The disadvantage of that approach is that an OPO can alter performance during that time, so the average will obscure the latest performance. The upside is avoiding one-year changes that are not maintained.

Average number of donors per 100 potential donors ranged from 16 (Connecticut) to 64 (Pittsburgh). Organ share ranged from 20 percent (Connecticut) to 77 percent (Pittsburgh). Full numbers are listed in Tables 5-8, along with numbers for some of the other potential metrics that were evaluated. Data tables for the measurements are available for download.

Nationally, the data was also evaluated to compare age groups and performance of organ collection overall, and by DCD and DBD. The results for the latest year of data, 2016, showed that OPOs gather more than the estimated organ potential from young people who die from brain death. But organ collection form older brain deaths and all cardiac deaths is far below the estimated potential. Results are shown in Table 4.

Responses from OPOs to the methodology and findings are appended after the results tables.

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2018-12-20

Table 1

Washington Post Replication of UNOS Deceased Donor Potential Study estimate from CDC-NCHS death certificate data

year	Actual deceased donors	Deceased Donor Potential Study (OPO Committee, NCHS Mortality)	Post replication
2003	6,457	36,316	36,338
2004	7,150	36,242	36,263
2005	7,593	36,463	36,477
2006	8,017	36,485	36,507
2007	8,085	37,208	37,214
2008	7,989	36,231	36,253
2009	8,022	35,615	35,619
2010	7,943	37,258	37,271
2011	8,126		37,652
2012	8,143		37,073
2013	8,269		37,181
2014	8,596		37,945
2015	9,079		39,354
2016	9,971		41,616

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Table 2

Washington Post replication of the 2017 study "Changing Metrics of Organ Procurement Organization Performance in Order to Increase Organ Donation Rates in the United States" (published in the American Journal of Transportation) that used National Inpatient Sample. Post used CDC-NCHS death certificate data.

year	deceased donors	2017 AJT study potential adjusting DBD-DCD (AHRQ NIS data)	Post Revised Potential DBD-DCD (NCHS Mortality/ CDC)
2003	6,457		23,157
2004	7,150		23,347
2005	7,593		23,524
2006	8,017		23,693
2007	8,085		24,391
2008	7,989		23,831
2009	8,022	24,007	23,458
2010	7,943	24,007	24,467
2011	8,126	24,007	24,899
2012	8,143	24,007	24,426
2013	8,269		24,380
2014	8,596		24,941
2015	9,079		25,812
2016	9,971		27,455

Table 3

Estimated number of organs adjusting for DBD and DCD deaths at rate of 3.3 for DBD and 1.9 for DCD based on Washington Post revised potential estimate.

Year	Deceased donors	Organs transplanted from deceased donors	The Post's Revised Potential DBD-DCD (NCHS Mortality/ CDC)	The Post's -- DBD	The Post's - DCD	Organ potential
2003	6,457	20,408	23,157	14,516	8,641	64,321
2004	7,150	21,966	23,347	14,538	8,809	64,713
2005	7,593	23,359	23,524	14,513	9,012	65,016
2006	8,017	24,504	23,693	14,501	9,192	65,318
2007	8,085	24,274	24,391	14,827	9,564	67,101
2008	7,989	23,979	23,831	14,536	9,295	65,629
2009	8,022	24,289	23,458	14,308	9,150	64,601
2010	7,943	24,665	24,467	14,928	9,539	67,387
2011	8,126	25,032	24,899	15,080	9,819	68,420
2012	8,143	24,625	24,426	14,848	9,578	67,197
2013	8,269	25,513	24,380	14,892	9,488	67,171
2014	8,596	26,110	24,941	15,198	9,744	68,667
2015	9,079	27,540	25,812	15,762	10,051	71,112
2016	9,971	30,497	27,455	16,668	10,787	75,500

Table 4

Organ share by age group and type of death for 2016.

2016	actual organs procurred	actual organs procurred from DBD	actual organs procurred from DCD	Post estimate organ potential	Post estimate potential organs from DBD	Post estimate potential organs from DCD	organ share	DBD organ share	DCD organ share
All Ages	35,361	31,135	4,226	75,500	55,003	20,496	47%	57%	21%
< 1 Year	446	389	57						
1-5 yr	780	709	71	2,080	1,320	760	37%	54%	9%
6-10 yr	486	457	29	830	527	303	59%	87%	10%
11-17 yr	2,166	1,998	168	1,522	966	556	142%	207%	30%
18-34 yr	13,120	11,686	1,434	10,425	6,616	3,809	126%	177%	38%
35-49 yr	9,099	7,754	1,345	12,515	7,942	4,573	73%	98%	29%
50-64 yr	7,744	6,644	1,100	28,720	18,226	10,494	27%	36%	10%
65 yr +	1,520	1,498	22	19,406	19,406	-	8%	8%	-

Table 5
Metric – Average donors per 100 potential donors

Name	Abbreviation	**Average 2014-2016 donors per 100 potential donors**
Center for Organ Recovery and Educ.	PATF	**64**
Nevada Donor Network	NVLV	**55**
Gift of Life Donor Program	PADV	**52**
Nebraska Organ Recovery System	NEOR	**52**
Midwest Transplant Network	MWOB	**47**
UW Health Organ and Tissue Donation	WIUW	**45**
The Living Legacy Foundation of MD	MDPC	**45**
Lifesharing - A Donate Life Org.	CASD	**43**
Washington Reg Transplant Community	DCTC	**42**
Southwest Transplant Alliance	TXSB	**41**
LifeLink of Florida	FLWC	**40**
LifeQuest Organ Recovery Services	FLUF	**39**
Gift of Hope	ILIP	**39**
LifeGift Organ Donation Ctr	TXGC	**38**
Donor Network of Arizona	AZOB	**37**
LifeShare Transplant Donor Svcs of OK	OKOP	**37**
Mid-America Transplant Svcs	MOMA	**36**
Intermountain Donor Services	UTOP	**36**
TransLife	FLFH	**36**
LifeShare of the Carolinas	NCCM	**35**
Upstate NY Transplant Svcs	NYWN	**35**
Wisconsin Donor Network	WIDN	**35**
Tennessee Donor Svcs	TNDS	**34**
Louisiana Organ Procurement Agency	LAOP	**34**
Donor Network West	CADN	**33**
Gift of Life Michigan	MIOP	**33**
OneLegacy	CAOP	**33**
Sierra Donor Services	CAGS	**33**
LifeBanc	OHLB	**32**
Life Alliance Organ Recovery Agency	FLMP	**32**
New England Organ Bank	MAOB	**31**
LifeSource Upper Midwest OPO	MNOP	**31**
LifeLink of Georgia	GALL	**31**
Legacy of Life Hawaii	HIOP	**30**

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NJ Organ and Tissue Sharing Network	NJTO	**30**
Donor Alliance	CORS	**30**
Life Connection of Ohio	OHLC	**29**
Pacific NW Transplant Bank	ORUO	**29**
LifeCenter Northwest	WALC	**29**
Indiana Donor Network	INOP	**28**
LiveOnNY	NYRT	**28**
LifeCenter Organ Donor Network	OHOV	**27**
Texas Organ Sharing Alliance	TXSA	**26**
New Mexico Donor Services	NMOP	**26**
Lifeline of Ohio	OHLP	**26**
Iowa Donor Network	IAOP	**25**
LifeNet Health	VATB	**25**
Carolina Donor Services	NCNC	**24**
Arkansas Reg. Organ Recovery Agency	AROR	**24**
Ctr for Donation and Transplant	NYAP	**24**
Mississippi Organ Recovery Agency	MSOP	**23**
Mid-South Transplant Foundation	TNMS	**22**
Alabama Organ Center	ALOB	**22**
LifePoint, Inc.	SCOP	**21**
Finger Lakes Donor Recovery Network	NYFL	**21**
KY Organ Donor Affiliates	KYDA	**20**
LifeChoice Donor Services	CTOP	**16**

Table 6

Average organs procured per 100 potential donors

Name	Abbreviation	Average 2014-2016 organs recovered per 100 potential donors
Center for Organ Recovery and Educ.	PATF	213
Nevada Donor Network	NVLV	202
Nebraska Organ Recovery System	NEOR	190
Gift of Life Donor Program	PADV	180
Midwest Transplant Network	MWOB	166
UW Health Organ and Tissue Donation	WIUW	157
Lifesharing - A Donate Life Org.	CASD	156
The Living Legacy Foundation of MD	MDPC	154
Southwest Transplant Alliance	TXSB	147
Washington Reg Transplant Community	DCTC	140
Gift of Hope	ILIP	139
Donor Network of Arizona	AZOB	134
LifeQuest Organ Recovery Services	FLUF	134
LifeGift Organ Donation Ctr	TXGC	133
Intermountain Donor Services	UTOP	132
LifeLink of Florida	FLWC	130
Mid-America Transplant Svcs	MOMA	128
LifeShare of the Carolinas	NCCM	128
Tennessee Donor Svcs	TNDS	126
Wisconsin Donor Network	WIDN	125
Louisiana Organ Procurement Agency	LAOP	125
Donor Network West	CADN	122
OneLegacy	CAOP	121
LifeShare Transplant Donor Svcs of OK	OKOP	121
Gift of Life Michigan	MIOP	118
LifeSource Upper Midwest OPO	MNOP	118
TransLife	FLFH	117
Sierra Donor Services	CAGS	115
Indiana Donor Network	INOP	112
LifeBanc	OHLB	112
Upstate NY Transplant Svcs	NYWN	111
Life Alliance Organ Recovery Agency	FLMP	110
Life Connection of Ohio	OHLC	109
NJ Organ and Tissue Sharing Network	NJTO	109
Donor Alliance	CORS	106
LifeLink of Georgia	GALL	105
LifeCenter Organ Donor Network	OHOV	104

New England Organ Bank	MAOB	103
LifeCenter Northwest	WALC	102
Texas Organ Sharing Alliance	TXSA	101
Pacific NW Transplant Bank	ORUO	96
LifeNet Health	VATB	94
Iowa Donor Network	IAOP	93
Lifeline of Ohio	OHLP	91
Legacy of Life Hawaii	HIOP	91
Arkansas Reg. Organ Recovery Agency	AROR	90
LifePoint, Inc.	SCOP	87
Carolina Donor Services	NCNC	86
LiveOnNY	NYRT	84
Mid-South Transplant Foundation	TNMS	83
New Mexico Donor Services	NMOP	81
Mississippi Organ Recovery Agency	MSOP	79
KY Organ Donor Affiliates	KYDA	72
Alabama Organ Center	ALOB	71
Ctr for Donation and Transplant	NYAP	68
Finger Lakes Donor Recovery Network	NYFL	64
LifeChoice Donor Services	CTOP	54

Table 7

Average organs transplanted per 100 potential donors

Name	Abbreviation	Average 2014-2016 organs transplanted per 100 potential donors
Center for Organ Recovery and Educ.	PATF	179
Nevada Donor Network	NVLV	172
Nebraska Organ Recovery System	NEOR	165
Midwest Transplant Network	MWOB	143
UW Health Organ and Tissue Donation	WIUW	142
Gift of Life Donor Program	PADV	136
Lifesharing - A Donate Life Org.	CASD	133
Southwest Transplant Alliance	TXSB	129
The Living Legacy Foundation of MD	MDPC	123
Intermountain Donor Services	UTOP	122
LifeLink of Florida	FLWC	119
Donor Network of Arizona	AZOB	117
Mid-America Transplant Svcs	MOMA	117
Gift of Hope	ILIP	116
LifeGift Organ Donation Ctr	TXGC	116
Washington Reg Transplant Community	DCTC	116
LifeQuest Organ Recovery Services	FLUF	115
LifeShare of the Carolinas	NCCM	113
Louisiana Organ Procurement Agency	LAOP	113
Donor Network West	CADN	107
Tennessee Donor Svcs	TNDS	107
LifeShare Transplant Donor Svcs of OK	OKOP	106
TransLife	FLFH	105
Wisconsin Donor Network	WIDN	103
Sierra Donor Services	CAGS	102
LifeSource Upper Midwest OPO	MNOP	101
Gift of Life Michigan	MIOP	101
OneLegacy	CAOP	99
Life Connection of Ohio	OHLC	99
Life Alliance Organ Recovery Agency	FLMP	99
Indiana Donor Network	INOP	98
LifeLink of Georgia	GALL	97
LifeCenter Organ Donor Network	OHOV	97
NJ Organ and Tissue Sharing Network	NJTO	96
LifeBanc	OHLB	95
Donor Alliance	CORS	93

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Texas Organ Sharing Alliance	TXSA	93
Upstate NY Transplant Svcs	NYWN	91
LifeCenter Northwest	WALC	91
New England Organ Bank	MAOB	89
Pacific NW Transplant Bank	ORUO	87
Iowa Donor Network	IAOP	84
Lifeline of Ohio	OHLP	81
LifeNet Health	VATB	80
Legacy of Life Hawaii	HIOP	79
LiveOnNY	NYRT	75
Arkansas Reg. Organ Recovery Agency	AROR	75
LifePoint, Inc.	SCOP	75
Carolina Donor Services	NCNC	74
Mid-South Transplant Foundation	TNMS	73
New Mexico Donor Services	NMOP	71
Mississippi Organ Recovery Agency	MSOP	70
KY Organ Donor Affiliates	KYDA	62
Ctr for Donation and Transplant	NYAP	61
Alabama Organ Center	ALOB	60
Finger Lakes Donor Recovery Network	NYFL	59
LifeChoice Donor Services	CTOP	48

Table 8

Average organ share

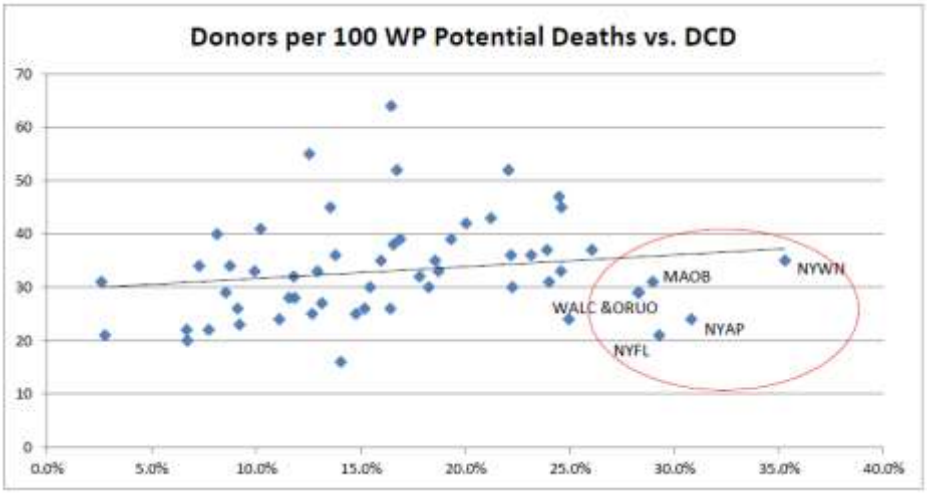
Name	Abbreviation	Average 2014-2016 organ share
Center for Organ Recovery and Educ.	PATF	77.5
Nevada Donor Network	NVLV	73.5
Nebraska Organ Recovery System	NEOR	68.6
Gift of Life Donor Program	PADV	64.9
Midwest Transplant Network	MWOB	60.3
Lifesharing - A Donate Life Org.	CASD	56.8
UW Health Organ and Tissue Donation	WIUW	56.6
The Living Legacy Foundation of MD	MDPC	56.4
Southwest Transplant Alliance	TXSB	53.8
Washington Reg Transplant Community	DCTC	51.1
Gift of Hope	ILIP	50.5
Donor Network of Arizona	AZOB	49.2
LifeGift Organ Donation Ctr	TXGC	48.8
LifeQuest Organ Recovery Services	FLUF	48.7
Intermountain Donor Services	UTOP	48.6
LifeLink of Florida	FLWC	47.3
LifeShare of the Carolinas	NCCM	46.7
Mid-America Transplant Svcs	MOMA	46.6
Wisconsin Donor Network	WIDN	45.6
Tennessee Donor Svcs	TNDS	45.6
Louisiana Organ Procurement Agency	LAOP	45.5
Donor Network West	CADN	44.3
LifeShare Transplant Donor Svcs of OK	OKOP	44.0
OneLegacy	CAOP	44.0
Gift of Life Michigan	MIOP	42.7
TransLife	FLFH	42.6
LifeSource Upper Midwest OPO	MNOP	42.5
Sierra Donor Services	CAGS	41.8
Indiana Donor Network	INOP	40.9
LifeBanc	OHLB	40.8
Upstate NY Transplant Svcs	NYWN	40.1
Life Alliance Organ Recovery Agency	FLMP	39.9
Life Connection of Ohio	OHLC	39.7
NJ Organ and Tissue Sharing Network	NJTO	39.2
Donor Alliance	CORS	38.7
LifeCenter Organ Donor Network	OHOV	38.3
LifeLink of Georgia	GALL	38.3

New England Organ Bank	MAOB	37.5
LifeCenter Northwest	WALC	37.1
Texas Organ Sharing Alliance	TXSA	36.8
Pacific NW Transplant Bank	ORUO	34.9
LifeNet Health	VATB	34.0
Iowa Donor Network	IAOP	33.6
Lifeline of Ohio	OHLP	33.2
Legacy of Life Hawaii	HIOP	33.1
Arkansas Reg. Organ Recovery Agency	AROR	32.5
LifePoint, Inc.	SCOP	31.5
Carolina Donor Services	NCNC	31.4
LiveOnNY	NYRT	30.5
Mid-South Transplant Foundation	TNMS	30.1
New Mexico Donor Services	NMOP	29.6
Mississippi Organ Recovery Agency	MSOP	28.8
KY Organ Donor Affiliates	KYDA	26.2
Alabama Organ Center	ALOB	25.6
Ctr for Donation and Transplant	NYAP	24.4
Finger Lakes Donor Recovery Network	NYFL	23.1
LifeChoice Donor Services	CTOP	19.6

Responses from Organ Procurement Organizations

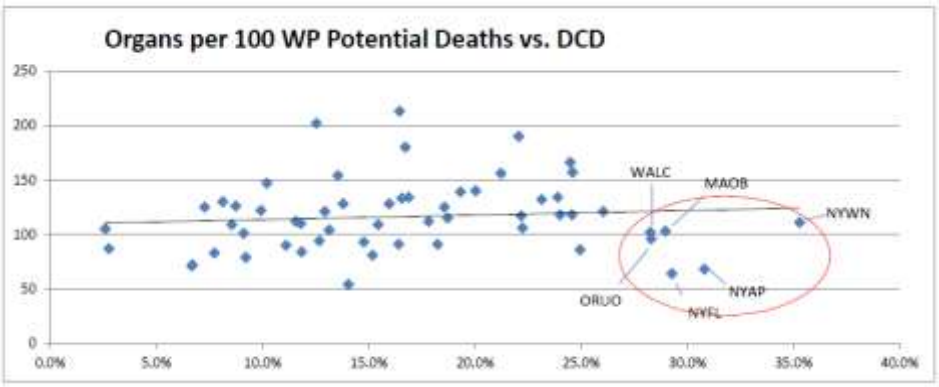
New England Donor Services

In regard to the metric, I've attached two scatter plots and the Excel spreadsheet of DCD data that support our concern that OPOs that do a good job identifying and converting DCD potential into actual DCD donors are disadvantaged by the Washington Post metric (both the transplant per 100 deaths and the donors per 100 deaths). OPOs that are already converting a large number of their DCD potential into actual DCD donors should rank favorably in a donation rate, however, the opposite appears to be the case with the Washington Post metric; the top performing OPOs with regard to DCD look comparatively worse under the Washington Post Metric than other metrics. None of the top 10 OPOs for DCD are in the top quarter under your metric. This points to a significant issue with the metric given that multiple studies have showed the largest potential for growth in the US is in DCD. The metric has to be better adjusted for DCD so as to properly evaluate true performance and to drive improvement - the two primary goals of a metric in my opinion. It the metric doesn't identify where an OPO has actual opportunity to improve, it is difficult to create operational strategies that will be effective.



To give you a sense of how off the metric seems compared to what we see on the ground: In 2016, New England Organ Bank received and processed 6,285 referrals calls from hospitals of patients that met clinical triggers for potential organ donation. Through a series of screens and medical assessments, 502 of those referrals were ultimately considered and categorized by NEOB as medically suitable for donation. However, while some of those referrals could be ruled in/ruled out by phone with information from the hospital, an NEOB coordinator responded onsite to the hospital for 1,539 of those referrals and made a further suitability assessment in person. This demonstrates that NEOB captures and assesses in person potential donors from a

very large set of referrals every year (3x the number eventually determined to be actually suitable) and is therefore not "missing" potential donors through the referral process. This is confirmed on death record review where the referral rate for NEOB has been 99+% for the last 5 yrs. This practice of going onsite in response to the broadest possible cut of potential is designed to ensure we are evaluating non-standard donors and DCD in particular. The performance outcomes show this - NEOB is one of the most aggressive DCD OPOs in the country per data attached. When you combine these facts with NEOB's underlying conversion rate of "eligible" donors (which is above average), this indicates that there is some very large over estimation of true DCD potential for NEOB in your metric – the denominator. And that the metric then further discounts actual DCD performance significantly given the expected transplant yield from DCD donors.



I hope you find this information helpful.

One of the biggest issues that remains with your metric is that it is based on an estimation of theoretical donor potential that does not map to actual potential. For NEOB in 2016 for example, we previously shared that it is significantly off. According to your metric there were theoretically 1,009 potential donors in the NEOB DSA in 2016. In reality, NEOB actually received and screened 6,285 referrals over the phone in 2016. Of that group NEOB staff assessed in-person 1,539 patients. Yet, after going on-site to the hospital, NEOB determined only 502 were actually medically suitable for donation. What explains that difference in your theoretical potential and what was actually determined as real potential in 2016? Where are the missing 507 potential donors? NEOB is clearly not missing referrals (we confirm this on death record review). Nor is NEOB screening out prematurely - OPO staff assessed on-site a pool of patients 52% larger than your theoretical potential donor pool in 2016. We can only conclude that your metric contains a significant over-estimation of NEOB's DCD potential – and NEOB is one of the most aggressive OPOs in DCD performance. Most likely your theoretical potential donor pool includes many patients with too much neuro who will not be asystolic within a time frame that permits

successful DCD after withdrawal of the ventilator. These are not actual potential DCD donors. Further, there is likely some regional variation to this over-estimation based on medical practice patterns such as access to early stroke interventions etc.

One other adjustment to a transplant yield metric that we did not discuss was donors that fall into the category of PHS increased risk – particularly donors that died from drug over-dose. Has anyone talked to you about that? Organs from these donors are much harder to place because of transmission risks and other outcome complications. The national average in 2016 of donors that died of drug over-dose was 13%. NEOB was at 27%. Just something else to consider. This is adjusted for in the SRTR observed to expected yield metrics.

In regard to the gap between supply and demand I have two comments:

First, there is more that can be done to increase transplant nationally and here in this region. The fact that NEOB is not missing cases at the referral and assessment stage doesn't result in a conclusion that we are "getting everything that's possible." To the contrary, there is room to improve NEOB's authorization rate and organ transplant yield per donor.

Ultimately, there is also room to expand what the transplant field today considers a medically suitable potential donor. But, as commented in the DDPS, this requires system-wide effort; OPOs cannot achieve this alone through "better performance". Currently transplant programs are not accepting and transplanting many organs that could provide benefit to patients waiting. As you likely know, in 2017 18.9% of recovered kidneys in the U.S. were discarded. Also expanding beyond standard of care definitions for donor suitability is key – see for example an article about HCV+ donors and heart transplant - O'Connor "An Innovative Approach to Increasing Donor Heart Supply: Will it Work? J. Cardiac Failure vol 23, No 10 (2017). We need transplant centers that are willing to accept and transplant organs from these donors in order to change standards of donor suitability over time. Having OPOs pursue and recover organs that don't get transplanted will not close the gap.

Second, importantly, there is no relationship between demand for transplant and donor potential. These are independent variables. So while that graphic is striking and important to understand, one cannot draw OPO donation performance conclusions from the gap.

Alexandra K. Glazier, Esq.
President & CEO
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Kentucky Organ Donor Affiliates

After reviewing the information provided, KYDA does not believe that the metrics put forth in support of your article accurately represents the true donor potential due to multiple variables. Specifically, you must be cognizant of the health, religious, and cultural differences that impact authorization and suitability for donation.

There are significant factors that influence the calculation of true organ donor potential including many that are outside the control of any OPO.

These include but are not limited to:

- How and when a family and their physician decide to withdraw ventilation
- Variability in disease co-morbidities such as cancer, smoking, diabetes, hypertension, obesity and heart disease, along with several other health factors

In our DSA, health status is consistently demonstrated to be one of the lowest in the country with high levels of obesity, smoking, diabetes, heart disease and cancer. These factors are among the donor specific information items that greatly impact the ability recover and transplant organs from KYDA's donor base. Because of this, KYDA believes you have significant overestimations as compared to the actual donation potential assessed through on-site medical screening of actual in-hospital patients and retrospective review of the factors around all hospital deaths for the years of data in question.

There are additional factors that are not accounted for in the calculation of potential organ donors, such as whether or not patients included in your pool of DCD actually died after ventilation was withdrawn within a time-frame that allows for organ donation to proceed. This is critical. Due to this fact, DCD donation potential cannot be accurately assessed; additional data is necessary to develop a complete picture of this potential pool of donors.

Our federal and association bodies strive to develop metrics that have technical integrity, are meaningful, understandable and adjusted for statistically significant data that is collected on all donor cases. KYDA works closely with these agencies and has met or surpassed standards to receive consistent recertification and accreditation. Through a process of continuous quality improvement, KYDA, and all OPOs, strive to increase the number of donations and transplants and ultimately save more lives.

KYDA is honored to serve our heroic donor families, transplant recipients and those still waiting. Our team continues to strive to meet the unending needs of this population every day. KYDA will continue to seek opportunities to spread education about donation and facilitate all donation opportunities within our service area.

Julie Bergin, RN, BSN, MHA

President and Chief Executive Officer

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LifeLink of Georgia / LifeLink of Florida

LifeLink is unable to support the Washington Post model, and therefore cannot sanction or agree with the results noted.

As previously shared, we are unable to verify or validate the data provided, because the proposed metric is unverified and not validated.

The numerous, significant variables that impact true donor potential don't appear to be adjusted for in the theoretical potential metric, such as access to healthcare, population, demographics, clinical practice, and detailed data of a patient's ventilator status, which is key.

While LifeLink did report data to the OPTN contractor as required by federal regulations, we have serious concerns about the Post's overstated determination of potential donors.

Please understand, LifeLink is committed to save the lives of waiting transplant recipients through organ donation, and to honor the decisions of generous donors and their families.

Ruth Duncan Bell, MPA
Senior Vice President, Public Affairs
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"A not-for-profit community service organiztion dedicated to saving lives through organ and tissue donation."

Thanks for the opportunity to review your data and provide comment. We have serious concerns about the methodology used to estimate "potential" donors. The specific formula you used is not clear within the spreadsheet. Your data significantly overestimates potential in our service area when compared to potential donors assessed through on-site medical screening of in-hospital patients and review of all hospital deaths in our region. Calculating donor potential is complex and involves many variables, human elements and clinical data that are not available through the CDC, and are unclear in your particular methodology.

With respect to donation after circulatory death (DCD) crucial factors to consider include: a patient's ventilator status, the supremely sensitive end-of-life decisions made by families and physicians regarding timing of ventilator removal, whether time of death following ventilator withdrawal is within a timeframe that allows for organ donation and more. Twenty two percent of Donor Alliance recoveries are from DCD donors over the referenced time frame of 2014-16, so we are intimately aware of how greatly the above factors impact DCD potential.

Our mission at Donor Alliance is to saves lives through organ and tissue donation and transplantation. Our core values are firmly integrated into all of our plans, decisions and behaviors, creating an organization that is truly mission-driven. In addition to our work to maximize donation potential, we also work tirelessly to educate the public on organ and tissue donation. Last year alone, 984,557 names in Colorado and 80,405 names in Wyoming were added to the organ and tissue donor registries. The donor designation rates reached 67.98 percent in Colorado and 58.58 percent in Wyoming - some of the highest rates in the country.

Despite these achievements, we do not rest. For more than eight years Donor Alliance has been on a concerted journey towards performance excellence. This striving for operational and organizational success is crucial to the lifesaving work that we do, and we are resolutely committed to continued improvement.

Andrea Smith
Donor Alliance

Director of PR/Communications
PH: 303-329-4747
asmith@donoralliance.org

Living Legacy Foundation of Maryland

I feel our data is accurately depicted within the context of this model. I do think the estimation of donor potential would be overstated based on the elements included in the denominator, however we have not yet solidified a data collection strategy for a better estimation of donor potential for our country. We are very close to agreeing on the construct of the model and will be in a better position soon, to understand the variability in organ availability in the US.

Charlie Alexander

The LLF's President and CEO

Wisconsin Donor Network

First and foremost, please know that we are completely aligned with the responses you have already received from AOPO. We believe strongly in the spirit, intent and process currently being followed by OPOs across the country. Our own team, as well as others around the country, are intensely passionate and dedicated, not only to building public awareness in order to encourage organ and tissue donation – but also to support our hospital partners. We work continuously and tirelessly to engage and inform hospital medical teams, as well as educate donor families and guide them through every step of the process once they have provided consent. And, most importantly, our team members are highly skilled, experienced, compassionate individuals. We all take our mission very seriously.

Having said that, no one is more keenly aware of the ongoing need than our team of professionals – who are dedicating their life's work to this mission. It is our belief that the greatest impact related to organ donation will come from more and more individuals signing the registry and generously committing to help others gain a second chance at life. That is our pursuit each day – through community events, story sharing, and community education through a variety of channels, along with providing the highest quality of service and care to hospitals and to donor families.

As experts in this area of care, we stand by AOPO's assessment that the donation potential you estimate is vastly over stated. It seems there are many factors that have not been accounted for in your findings. For instance, the timing and consideration of sensitive donor family decision-making, as well as other health related variables, are tender human components that cannot be easily computed when developing measurements and formulas.

In addition, you may be aware that **less than 1%** of people who die in hospitals are potential organ donors, since potential organ donors must be on a ventilator and die from brain death, or – in certain situations – cardiac death.

We appreciate the opportunity to provide our viewpoint on a very critical and sensitive topic. I hope you strongly consider the feedback you receive from organ donation organizations such as ours. We greatly value awareness about the ongoing need for donation, but we are also very mindful that stories that diminish the work being advanced by professional, passionate and committed individuals, can serve to damage, rather than further the mission of extraordinary organizations committed to this cause.

Colleen McCarthy, Vice President

BloodCenter of Wisconsin, Wisconsin Donor Network and Tissue Bank

Statement from LifeNet Health:

Douglas B. Wilson

Upon review of *The Washington Post's* theoretical metrics on potential organ donors in an OPO DSA, we conclude it is not an accurate assessment of the true number of medically suitable potential organ donors in the LifeNet Health DSA. Using an opening age cap (75) as the baseline criteria does not include the multiple necessary clinical filters needed to define a DSA's true pool of medically suitable potential organ donors.

The *Post's* data, driven by various newly introduced assumptions, appears to inadvertently over predict the actual number of potential organ donors in this Virginia DSA.

Our validated data, which is derived from onsite and retrospective medical-record reviews of all hospital deaths, does not correlate with the *Post's* theoretical metrics. As you point out, you have "an estimated donor pool;" our data collection and review process gives us an accurate assessment of true donor potential for the DSA.
While we applauded any assistance from the *Post* in transplanting more patients in the United States needing an organ, the current validated metrics provide us with the true pool of medically suitable potential organ donors in this DSA.

PDF via electronic mail

August 11, 2018

Dan Keating
Reporter Data/Graphics
The Washington Post

Re: Washington Post inquiry on data about LifeShare (OKOP) – your e-mail of 8/9/2018

Dear Mr. Keating,

I am writing in response to your e-mail dated 8/9/2018, in which you shared an analysis performed by the Washington Post. You state "we replicated the OPO Committee portion of the Deceased Donor Potential Study that used CDC mortality data from death certificates, and extended it through the most recent CDC data in 2016. We also modified the analysis based on a study published last year in the Amer. Journal of Transplantation that reduces the estimated potential based on data showing a much lower donor potential for cardiac death."

Attached to your inquiry was an Excel spreadsheet depicting the data obtained from CDC, OPTN, and SRTR concerning the 58 DSA's in the United States including our own (LifeShare Transplant Donor Services of Oklahoma, hereafter referred to as OKOP or LifeShare). In your communication, you acknowledged that "AOPO and some OPOs" have provided a critique of the analysis including saying the estimates are too high.

As you are likely aware, I have spoken to both Kimberly Kindy (on multiple occasions) and Lenny Bernstein (once) of your paper regarding this story, our success in doubling organ donation in Oklahoma from 2013 to 2016, and specifically regarding the flaws in the Deceased Donor Potential Study (DDPS). Having reviewed the data and graphics you provided, I would offer the following commentary in response to your model's assessment which "showed that LifeShare recovered 44% of the potential estimated organs in 2014-2016" compared to a range of 20% to 77% and an average of 42% as estimated by your model.

- The DDPS is inherently flawed as it omits, and in fact must omit, relevant clinical data necessary to project donor potential that is simply not available through the CDC. Two examples of flaws in the DDPS are:
    - To effectively estimate donation after circulatory death (DCD) potential, it is essential to know how long any deceased individual survived after withdrawal of the ventilator and life-sustaining therapy; this data is not available from the CDC and without it, it is impossible to determine whether any death meets the current criteria for DCD most U.S. transplant centers require which is circulatory cessation and pronouncement of death within 60-120 minutes.
    - Similarly, estimating donation after brain death (DBD) potential requires some level of clinical assessment of organ function; not every person who is declared brain dead is in fact medically suitable to donate an organ. Clinical assessment data is not sufficiently

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