National Deceased Organ Donation Potential Study: Overview and Next Steps

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Acknowledgements

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  - Linda P. Fried, MD, MPH, Dean
  - Sandro Galea, MD, DrPH, Chair, Department of Epidemiology
  - Roger Vaughan, DrPH, Chair, Department of Biostatistics
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- **HRSA, Division of Transplantation**

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Presentation Overview

- Describe Background and Significance of Problem
- Examine the Population and Context of Deceased Donor Potential
- Present Study Overview, Design, and Key Project/Analytic Activities
Introduction System Dynamics Framework and Models
Transplantation: A Systems View

- Efficient Transplant Care
- System and Workforce Standards, Innovation and Improvements
- Increase Organ Supply
- Preventive Care Initiatives that Reduce or Curb Demand for Organs
- Long, Healthy, and Productive Lives for Persons with End-Stage Organ Failure
- Effective, High Quality and Safe Care
- Equitable Organ Allocation and Access

Adapted from The Commonwealth Fund. Framework for a high performance health system for the United States.
Background and Significance of Deceased Donation Potential

- **Background**
  - Success of transplantation as a viable clinical intervention for persons with end-stage organ failure is reflected in its impact on modern medicine.
  - Total number of persons transplanted from deceased donors over the past two decades approaches 450,000.
  - Donor families life-saving gifts enable many to live longer, healthier, and productive lives than without it.
Background and Significance of Deceased Donation Potential-II

- **Significance**
  - Importance of Topic to Progress in the Field
    - Need for transplantable organs continues to increase.
      - Morbidity
        - Burden of illness in population.
    - Demand for transplant services
      - Demand continues to exceed supply.
  - Pattern of deceased donation over time.
  - Mortality--Annual number of deaths versus eligible deceased donors.
  - Can we really close the gap?
Chronic Diseases are the Leading Causes of Death and Disability in the U.S.

- 7 out of 10 deaths among Americans each year are from chronic diseases. Heart disease, cancer and stroke account for more than 50% of all deaths each year.\(^1\)
- In 2005, 133 million Americans – almost 1 out of every 2 adults – had at least one chronic illness.\(^2\)
- Obesity has become a major health concern. 1 in every 3 adults is obese\(^3\) and almost 1 in 5 youth between the ages of 6 and 19 is obese (BMI $\geq$ 95th percentile of the CDC growth chart).\(^4\)
- About one-fourth of people with chronic conditions have one or more daily activity limitations.\(^5\)
- Diabetes continues to be the leading cause of kidney failure, nontraumatic lower-extremity amputations, and blindness among adults, aged 20-74.\(^7\)

Chronic Disease as a Driver for Transplantation Demand: A Look at Chronic Kidney Disease and the Migration to End-Stage Renal Failure

United States Renal Data System (USRDS)
2010 and 2012 Annual Data Reports
Adjusted Incident Rates of ESRD and Annual Percent Change

Figure 1.2 (Volume 2)


Adjusted Prevalent Rates of ESRD and Annual Percent Change

Figure 1.10 (Volume 2)

December 31 point prevalent ESRD patients.
Adj: age/gender/race; ref: 2005 ESRD patients.

Geographic Variations in Adjusted Prevalent Rates (per million population), 1998

Figure 2.11 (Volume 2)

Geographic Variations in Adjusted Prevalent rates of ESRD per million population, 2010, by HSA

Figure 1.11 (Volume 2)

Examining the Population of Potential Donors
Deceased Donor Process for Organ Donation

1. Referred deaths
2. Eligible deaths
3. Consented donors
4. Recovered organs
5. Transplanted organs
6. Deceased donors

Source: 2004 OPTN/SRTR Annual Report
General Approach to the Process of Deceased Donation after Brain Death

1. Identification
   - Severely brain damaged patient
   - Brain Death possible

2. Evaluation
   - Brain Death possible with no medical contraindications
   - Brain Death possible with no medical contraindications

3. Confirmation and legal declaration of Brain Death
   - Maintenance
     - Failure to identify/refer
     - Medical Contraindications
     - Diagnosis of Brain Death not completed

4. Consent to organ donation

5. Organ recovery

Potential of donation

Effective (=actual) donor

Effectiveness

Areas for improvement

Path from Mortality to Deceased Donors: Levels of Data, Comprehensiveness, and Inclusions/Exclusions

1. All Deaths
2. All Medically Suitable Deaths
3. OPTN Database or Registry
4. Donors
## Understanding Mortality

### 10 Leading Causes of Death by Age Group, United States - 2010

<table>
<thead>
<tr>
<th>Rank</th>
<th>&lt;1</th>
<th>1-4</th>
<th>5-9</th>
<th>10-14</th>
<th>15-24</th>
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<td>1</td>
<td>Congenital Anomalies 5,107</td>
<td>Unintentional Injury 1,394</td>
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<td>Unintentional Injury 12,341</td>
<td>Unintentional Injury 14,573</td>
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<td>Malignant Neoplasms 50,211</td>
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<td>Heart Disease 477,338</td>
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<td>Short Gestation 4,148</td>
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<td>Malignant Neoplasms 439</td>
<td>Malignant Neoplasms 477</td>
<td>Homicide 4,878</td>
<td>Suicide 5,795</td>
<td>Malignant Neoplasms 11,809</td>
<td>Heart Disease 36,729</td>
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<td>3</td>
<td>SIDS 2,063</td>
<td>Homicide 385</td>
<td>Congenital Anomalies 163</td>
<td>Suicide 267</td>
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<td>Heart Disease 10,594</td>
<td>Unintentional Injury 19,867</td>
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<td>Homicide 111</td>
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<td>Congenital Anomalies 135</td>
<td>Heart Disease 1,028</td>
<td>Heart Disease 3,222</td>
<td>Homicide 2,473</td>
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<td>Diabetes Mellitus 11,877</td>
<td>Alzheimer's Disease 82,816</td>
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<td>Placenta Cord. Membranes 1,030</td>
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<td>Perinatal Period 52</td>
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<td>Necrotizing Enterocolitis 472</td>
<td>Chronic Low Respiratory Disease 51</td>
<td>Septicemia 32</td>
<td>Septicemia 35</td>
<td>Complicated Pregnancy 163</td>
<td>Congenital Anomalies 397</td>
<td>Influenza &amp; Pneumonia 773</td>
<td>Viral Hepatitis 2,376</td>
<td>Septicemia 4,604</td>
<td>Septicemia 26,310</td>
<td>Suicide 38,364</td>
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Data Source: National Vital Statistics System, National Center for Health Statistics, CDC.
Produced by: Office of Statistics and Programming, National Center for Injury Prevention and Control, CDC using WISQARS™.
Understanding Deceased Donor Characteristics from Actual Donors

Source: Organ Procurement and Transplantation Network (OPTN) Data Report
http://optn.transplant.hrsa.gov/data/ and Scientific Registry of Transplant Recipients (SRTR)
Deceased Donor Characteristics, 2000-2012, Death Circumstance, Any Organ

- MVA
- Suicide
- Homicide
- Child Abuse
- Non-MVA
- Other

*Note: “Other” Category = Natural causes + None of the other death circumstances
Deceased Donor Characteristics, 2000-2012, Cause of Death, Any Organ

*Note: “Other” Category = Natural causes + None of the other death circumstances
Deceased Donor Characteristics, 2000-2012
Mechanism of Death, Any Organ

![Graph showing mechanism of death for deceased donors from 2000 to 2012.](chart)

- **Drowning**
- **Seizure**
- **Drug Intoxication**
- **Asphyxiation**
- **Cardiovascular**
- **Gunshot/Stab**
- **Blunt Injury**
- **SIDS**
- **Intracranial Hemorrhage/Stroke**
- **Natural Causes**
- **Other**
Deceased Donor Characteristics, 2000-2012
Deceased Donors by Brain Death (DBD) and Donation after Circulatory Death (DCD), Any Organ

Number of Deceased Donors by Type

Year

DCD
DBD

OPTN
Deceased Donor Characteristics, 1988-2012
Deceased Donors Recovered by Gender, Any Organ

Number of Deceased Donors

Year


Male
Female
Deceased Donor Characteristics, 1988-2012
Donor Ethnicity/Race, Any Organ

Number of Deceased Donors

Year


White
Black
Hispanic
Unknown
Asian
American Indian/Alaska Native
Pacific Islander
Deceased Donor Organ Utilization, 2002-2011

Any Organ

Number of Deceased Organ Donors

Year

<table>
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<th>Year</th>
<th>Total # Donors of Any Organ</th>
<th># Any Organ Recovered</th>
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<td>2002</td>
<td>6,190</td>
<td>22,391</td>
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<td>2003</td>
<td>6,457</td>
<td>22,896</td>
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<td>2004</td>
<td>7,150</td>
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<td>2005</td>
<td>7,593</td>
<td>26,811</td>
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<td>2006</td>
<td>8,019</td>
<td>28,208</td>
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<td>2007</td>
<td>8,086</td>
<td>28,287</td>
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<td>2008</td>
<td>7,990</td>
<td>27,843</td>
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<td>2009</td>
<td>8,022</td>
<td>28,258</td>
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<td>2010</td>
<td>7,943</td>
<td>28,405</td>
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<tr>
<td>2011</td>
<td>8,125</td>
<td>28,793</td>
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</table>
Deceased Organ Donation: Overall & organ-specific donation rates per eligible deaths, 2011, SRTR
Deceased Organ Donation: Overall donation rates (per 100 eligible deaths), by DSA, 2011, SRTR
SUMMARY

- Number of deceased donors increased around 2003, but has remained relatively stable over the last 5-7 years; total number of donors during this period ranged from 6009-8143
- Percentage (%) of donors who are DCD has increased substantially in most recent years, up to 13% in 2011
- COD:
  - Most frequent is head trauma; previously was cerebrovascular/stroke
  - Greatest increase was in deaths due to anoxia
- Mechanism of death:
  - Most frequent is intracranial hemorrhage/stroke; next most common was blunt injury
  - Greatest percentage increase was in cardiovascular deaths.
- Circumstance of death:
  - Most frequent is “other”, which includes death from natural causes and deaths that do not fall into any of the other categories (i.e., none of the above).
  - Number of donors with MVA as circumstance declined over this period.
OPTN Deceased Donor Potential Study (DDPS)
The DDPS aims to generate more current scientific evidence that is based on rigorous epidemiologic and demographic analyses of the deceased donor system for the purposes of determining the potential number of organ donors, and to determine the potential trend in that number over time.
The “Question”

- What is the “true” potential for deceased organ donation in the United States?
Study Design Concepts
Requested by HRSA

Methods

- Population-based inquiry
- Demographic methods
- Epidemiological approaches
- Trend analysis
- Systems Science (CTSE recommendation)
Important Qualifiers or Clarifying Points about the Study

What the study is not:

- Does not include OPTN policy formation and analysis.
- Does not include any focus on organ allocation or distribution.
- Does not include any recommendations on differing geographic units of measure or operational approaches.
- Study is not focused on current understandings or classifications typically used for compliance reasons (ECD, SCD, etc.).
# The Research Team

<table>
<thead>
<tr>
<th>Name and Organizational Affiliation</th>
<th>Specialty Area</th>
<th>Role on Team</th>
</tr>
</thead>
<tbody>
<tr>
<td>L. Ebony Boulware, M.D., M.P.H. (Hopkins)</td>
<td>Internal Medicine, Chronic Disease Epidemiology</td>
<td>Co-Investigator</td>
</tr>
<tr>
<td>Leah B. Edwards, Ph.D. (UNOS Research)</td>
<td>Biostatistics, Clinical Registries</td>
<td>Co-Investigator</td>
</tr>
<tr>
<td>Gary King, Ph.D., M.A. (Harvard)</td>
<td>Quantitative Methods, Mortality Studies</td>
<td>Co-Investigator</td>
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<tr>
<td>Kevin A. Myer, M.S.H.A. (LifeGift)</td>
<td>Organ Procurement</td>
<td>Co-Investigator</td>
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<tr>
<td>Michael Reibel, Ph.D. (Cal Poly)</td>
<td>Geography, Demography</td>
<td>Co-Investigator</td>
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<tr>
<td>John D. Rosendale, M.S. (UNOS Research)</td>
<td>Biostatistics, OPO Performance</td>
<td>Co-Investigator</td>
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<tr>
<td>Khalid Saeed, Ph.D., M. Eng. (WPI)</td>
<td>System Dynamics, Economics</td>
<td>Co-Investigator</td>
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<tr>
<td>Laura A. Siminoff, Ph.D., M.A. (VCU)</td>
<td>Organ Donation, Decision Making and Decision Aids</td>
<td>Co-Investigator</td>
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<tr>
<td>Samuel Soret, Ph.D., M.P.H. (Loma Linda U)</td>
<td>Health Geoinformatics</td>
<td>Co-Investigator</td>
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<tr>
<td>Gary B. Hirsch, S.M. (MIT)</td>
<td>System Dynamics</td>
<td>Co-Principal Investigator</td>
</tr>
<tr>
<td>Karl J. McCleary, Ph.D., M.P.H. (UNOS CTSE and VCU)</td>
<td>Health Systems Management and Policy</td>
<td>Principal Investigator</td>
</tr>
</tbody>
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DDPS : How the Work Get’s Done

<table>
<thead>
<tr>
<th>The Committee</th>
<th>The Subcommittees</th>
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<tbody>
<tr>
<td><strong>DDPS Stakeholder Committee</strong> is comprised of transplant and non-transplant professionals (50 members)**</td>
<td><strong>OPO Subcommittee</strong></td>
</tr>
<tr>
<td>• Critical Care, Neuro, Trauma, Emergency Medicine</td>
<td><strong>Data Subcommittee</strong></td>
</tr>
<tr>
<td>• OPO Professionals (Executives, Directors of Procurement, Clinical Operations, Communications, Quality Improvement)</td>
<td><strong>Caregiver Informant Group Subcommittee</strong></td>
</tr>
<tr>
<td>• Transplant Surgeons and Physicians, Transplant Nurses</td>
<td><strong>System Dynamics Work Group</strong></td>
</tr>
<tr>
<td>• Other Subject Matter Experts—Geography, Epidemiology, Economics, Health Services Research, Statistics, System Dynamics, and Human Subjects Protection</td>
<td><strong>Evidence-Based Review Subcommittee</strong></td>
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<tr>
<td>• Transplant Recipient and Citizen Participant</td>
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<td>• HRSA</td>
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<td>• CMS</td>
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<td>• AHA</td>
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Specific Aims: Goals and Associated Research Questions

Goal 1:
To accurately characterize the current size and composition of deceased donation in the United States.

• Research Question: What is the current state of deceased donation in the United States?

• Corollary Research Questions:
  • What are the emergent patterns of deceased donation over time in the United States?
  • What patterns of deceased donation are characterized or reflected in population and demographic factors?
  • What patterns of deceased donation are characterized or reflected nationally and in regional donation service areas (DSAs) or other appropriate designated geographies/geographic areas?
  • What patterns of deceased donation are characterized or reflected in the recovery and utilization of various organs?
Specific Aims: Goals, Objectives, and Research Questions

Goal 2:
To accurately characterize the *predicted size and composition* of the deceased donor potential pool in the United States over the next five to ten years.

- **Research Question:**
  - What is the actual potential for deceased organ donation in the United States?
    - What is the actual potential nationally?
    - What is the actual potential regionally (i.e., non-administrative or political boundaries) and in associated localities?
- **Corollary Research Questions:**
  - What is the predicted size and composition of the deceased donor potential pool nationally and regionally in the United States?
  - Why are certain aspects of the deceased donor organ system changing?
Specific Aims: Goals, Objectives, and Research Questions

Goal 3: To provide a rigorous empirical foundation for developing National goals for deceased organ donation within the context of the system’s true donor potential.

- Research Question:
  - What *evidence-based, realistic National goals* can be set for deceased organ donation within the context of a rigorous empirical examination of the system’s true donor potential? *(HRSA’s Task with Community Input)*
  - What *rigorous, evidence-based empirical methods can be employed*, within the context of the system’s true donor potential, to set or establish realistic National goals for deceased organ donation? *(Research Team’s Task with Stakeholder Committee Input)*

- Corollary Research Questions:
  - What are the anticipated trends in the deceased donor organ system change over the next five to ten years?
Specific Aims:
Goals, Objectives, and Research Questions

Goal 4:
To inform HRSA’s strategic planning process to identify and implement methods that increase deceased organ donation.

- **Research Question:**
  - What options would best govern potential changes in the deceased donor transplant system that will increase organ donation?

- **Corollary Research Questions:**
  - Where is the deceased donor system headed if no new action is taken?
  - How else can the deceased donor system behave, if different decisions are made?
  - Who has the power to move the deceased donor system in a better, more sustainable direction?
Use system dynamics as an unifying framework for understanding deceased donor potential, linking existing bodies of knowledge and specific research traditions that are relevant to transplantation WITH the power of system science.

Examine deceased donor potential from a complex system view.
Research Strategy

System Dynamics — View Deceased Donor Potential within the context of Organ Procurement and Transplantation as a Complex Adaptive System

Complexity of Deceased Donor Potential within the Transplant System—Donation Service Area, Regional, National

Dynamics of Deceased Donor Potential within the Transplant System

Mortality Population-Based
Demographics, Geography
Epidemiology
Causal Relationships, Trends/Patterns over Time

OPTN
Deceased Donor Potential Study

- Donor Potential Number
- Donor Gap Analyses
- Donor Potential Projections
Deceased Donor Potential Study
Subcommittee Contributions

- Donor Potential Number
- Donor Potential Projections
- Donor Gap Analyses

- Caregiver Informant Group
- Data Subcom Evidence-based Review
- OPO Subcommittee System Dynamics Team
- Open Innovation

OPTN
Data source triangulation for Donor Potential Number

- The CIG, OPO, and Data Subcommittees will collaborate to provide three different estimates of donor potential using different databases and similar filters.
- This range of estimates will also be used in the System Dynamics Deceased Donor Potential model.
## Data Source Options

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<th>Data Source</th>
<th>Strengths</th>
<th>Limitations</th>
<th>DDPS Project Utility</th>
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<tbody>
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<td>National Mortality Data NVSS</td>
<td>Includes all deaths</td>
<td>Not coded for all medical exclusionary criteria</td>
<td>Use for DDP Estimate #1</td>
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<td>National Hospital HCUP</td>
<td>Includes all medically relevant exclusionary criteria</td>
<td>Includes only deaths occurring in hospitals; No COD data</td>
<td>Use for DDP Estimate #2</td>
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<td>OPO Medical Record Reviews</td>
<td>Includes medically relevant criteria</td>
<td>Disparate, non-standard formats</td>
<td>Time required not available</td>
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<tr>
<td>OPO Call Center Records</td>
<td>Rich source of qualitative data</td>
<td>Will not provide DDP per se</td>
<td>Time required not available</td>
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<td>California Mortality Data</td>
<td>Includes complete, identified mortality data allowing linking to UNOS database; 10-yr series</td>
<td>Includes only California deaths</td>
<td>Use for DDP Estimate #3 and Gap Analyses</td>
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Key Analysis: Computing Overall Donor Potential

1. NVSS Data
2. Apply Inclusionary and Exclusionary Criteria
3. Extract Records for Donor Suitable Deaths
4. Count Records (=Donor Potential)
5. Suitable Deaths Database
6. (To Subanalyses)
Procedure for Developing and Applying Custom Criteria for Medical Suitability/Unsuitability for Donation

1. Inclusionary and Exclusionary Criteria from Clinicians and Caregivers

2. Synthesize and Operationalize Criteria Within the Constraints of Available Data (Core Research Team)

3. Inclusionary and Exclusionary Criteria from OPO Leaders and Procurement Professionals
Donor Potential Estimate #1

1. All Deaths
2. All Medically Suitable Deaths
3. OPTN Database
4. OPTN Donors

Inclusionary and Exclusionary criteria:
- CIG Review and Modify for Clinical Accuracy per Organ
- Use as filter for HCUP data

Healthcare Cost and Utilization Project Data:
- Filter deaths with revised clinical inclusionary and exclusionary criteria
- Analysis includes sensitivity ranges

Deceased Donor Potential Range Estimate #1:
- Purely clinical criteria
- Hospital patients only

OPTN
Donor Potential Estimates #2 & #3

NVSS National Mortality
- Filter deaths with synthesized inclusionary and exclusionary criteria

California National Mortality
- Filter deaths with synthesized inclusionary and exclusionary criteria

Deceased Donor Potential Estimate #2
- Includes deaths
- May not capture medical suitability not diagnosed at time of death

Deceased Donor Potential Estimate #3
- May not capture medical suitability not diagnosed at time of death
- Includes only California deaths
- Link to OPTN data

Inclusionary and Exclusionary criteria
- CIG Review and Modify
- OPO review and modify
- Synthesize above for filter

OPTN Donors
1. All Deaths
2. All Medically Suitable Deaths
3. OPTN Database
4. OPTN Donors
Donor Potential Gap Analysis

- Use logistic regression models using census covariate data to determine probability of
  1. Donation if eligible
  2. OPTN Database - if medically suitable
  3. OPTN Donor - if medically suitable
Data Source and Database Summary

- **A.** National Vital Statistics System
  Multiple Cause of Death Microdata (=“NVSS”)

- **B.** Experimental Baseline Mortality Data (=“Mortality Baseline”)

- **C.** Organ Procurement and Transplant Network Imminent Deaths Microdata (=“OPTN”)

- **D.** County Level Demographic, Social, Geographic Covariates from U.S. Census (=“Census”)

**Extract**

- Comprehensive Database of all Donor Suitable Deaths (=“Suitable Deaths”)
- Suitable Donors Experimental Database (=“Suitable Baseline”)
- Donors Database (=“Donors”)

**Note:** the NVSS data cannot be merged. Experimental “B” data will be match merged to the OPTN and Donor data sets for direct comparative modeling. Experimental baseline data must include all deaths but can be limited in scope (i.e. one or more states rather than U.S.)
Donor Potential Projections: Policy Implications

- What policies are most effective to increase donation and increase realization of deceased donor potential?
Deceased Donor Potential for Organ Transplantation: A System Dynamics Framework
# Kidney Transplant Overview

## US Kidney Statistics for 2011

<table>
<thead>
<tr>
<th>Description</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deceased Kidney Transplant Donors</td>
<td>6,396</td>
</tr>
<tr>
<td>Deceased Donor Transplants</td>
<td>11,042</td>
</tr>
<tr>
<td>Living Donor transplants</td>
<td>5,771</td>
</tr>
<tr>
<td>Total Waitlist</td>
<td>90,468</td>
</tr>
<tr>
<td>Active Waitlist</td>
<td>62%</td>
</tr>
<tr>
<td>Added</td>
<td>33,581</td>
</tr>
<tr>
<td>Removed*</td>
<td>28,629</td>
</tr>
</tbody>
</table>

* Including Transplants
Overview of donor potential, organ procurement, and transplantation system
Donor potential and organ procurement characterized as a narrowing funnel of deaths
Flows of People Associated with Transplantation

- New Cases of Organ Failure
- People with End Stage Organ Failure
- People on Waiting Lists
- Transplanted Patients
- Deaths
- Transplant Rate
- Capacity

Organs Available for Transplantation

Organ Procurement

OPTN
Deceased Donor Kidney Transplants (US 2001-2009)

Historical Transplant Rate

Years

Historical Transplant Rate

OPTN
Kidney Waiting List (US 2001-2009)
Organ acceptance based on quality considerations

Outcomes: Patient and Graft Survival

Organ Acceptance Rate

Average Quality of Transplanted Organs

Transplant Rate

Organs Available for Transplantation

OPTN
Organ acceptance constrained by transplant program capacity and goals

- Transplant Program Capacity and Goals
- Organ Acceptance Rate
- Organs Available for Transplantation
- Outcomes: Patient and Graft Survival
- Average Quality of Transplanted Organs
- Transplant Rate

A

B

OPTN
Organ availability constrained by OPO efforts and criteria

- Organ Acceptance Rate
- Average Quality of Transplanted Organs
- Outcomes: Patient and Graft Survival
- Transplant Program Capacity and Goals
- Organs Offered
- Selected Donors
- Organs Available for Transplantation
- Transplant Rate
- Organ Available
- A
- B
- C
- OPO Efforts and Criteria
- OPO Measurement

OPTN

UNOS DONATE LIFE
UNITED NETWORK FOR ORGAN SHARING
Results of Baseline Simulation
Transplant rate as affected by policy to adjust transplant capacity
Transplant rate as influenced by aggressive campaigns to sign up organ donors
Effects of Increased Entries to Waiting Lists
Effect of higher rate of referrals to OPOs
Effect of relaxing (perceived) quality constraints on organ acceptance

![Graph showing successful transplants per year from 2001 to 2021. The graph indicates an increase in successful transplants over time.]
Results of combined strategy with increased referral from hospitals and relaxed quality constraints on organ acceptance.
Effect of Adding a (Previously Weak) Policy to a Combined Strategy
## Characteristics of the Three donation Service Areas (DSA’s) to Which the Model Was Applied

<table>
<thead>
<tr>
<th>Donation Service Area/Organ Procurement Organization</th>
<th>New England Organ Bank</th>
<th>Alabama Organ Center</th>
<th>OneLegacy (California)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population Served</td>
<td>11,591,545</td>
<td>4,913,524</td>
<td>19,035,357</td>
</tr>
<tr>
<td>Total Transplants (2011)</td>
<td>612</td>
<td>249</td>
<td>864</td>
</tr>
<tr>
<td>Living Donors</td>
<td>260</td>
<td>106</td>
<td>255</td>
</tr>
<tr>
<td>Deceased Donors</td>
<td>352</td>
<td>143</td>
<td>609</td>
</tr>
<tr>
<td>Total Waiting List (2011)</td>
<td>2957</td>
<td>3404</td>
<td>6128</td>
</tr>
<tr>
<td>Percent Active</td>
<td>62</td>
<td>63</td>
<td>77</td>
</tr>
</tbody>
</table>
Policy Results for New England Organ Bank (1)
Policy Results for New England Organ Bank (2)

1. Base run
2. Timely death referral
3. Wide quality acceptance
4. Policy 2+3 + increased referral to waitlist
System Dynamics Model: Results

- Conceptual model that integrates insights from stakeholder discussions and contributions at meetings, stakeholder survey, and interviews with staffs of several OPOs and transplant programs, and UNOS staff.

- Improved understanding of the constraints on realizing donor potential

- Quantitative model calibrated for the kidney procurement and transplantation for the US as a whole and for three DSA’s that represent a cross-section of different populations and donor volumes

- Simulation results at the National and DSA levels that help us understand how the realization of donor potential is sensitive or insensitive to various policies
Realization of donor potential is constrained by the manner in which the organ procurement and transplantation system functions. The rules and measurement systems may, in some cases, work against increases in volume and contribute to the plateauing of transplant volumes for the past several years.

Changing the system by which transplant programs are measured to create a better balance between outcomes such as graft failure and the number of people who are helped by transplants may help to increase volume by making programs less risk averse and more willing to transplant organs from less-than-ideal donors.
Increasing the rate at which people sign up for donor registries can have a marginal effect on realization of donor potential by helping to improve conversion rates. The volume is still limited by the referral of medically suitable donors to the OPO’s.

Increasing the flow of patients to active waiting lists can also have a marginal effect in increasing volume by creating more pressure to accept organs from less-than-ideal donors and making it more likely that a good match will be found for organs offered to transplant programs.

Measurement of OPO’s based on conversion rates and organs per donor may limit pursuit of potential donors by making the OPO’s more conservative about the range of potential donors they consider.
Increases in the volume of timely referrals from hospitals and the fraction of referrals OPO’s pursue can increase the volume of organs available for transplantation without reducing the average quality.

Strategies utilizing multiple approaches that are mutually reinforcing are likely to have the greatest impact in improving the realization of donor potential.
System Dynamics Model: Additions to the Field of Organ Procurement and Transplantation

- New technique, not applied in the field before; new way of thinking about how organ procurement and transplantation function as a system

- Framework for integrating diverse viewpoints about parts of the system into a coherent whole that can be used to assess the impact of policy changes on realization of donor potential and increases in transplant volume

- Insights about relative leverage of policies for increasing realized donor potential and how this might differ in DSA’s with various characteristics
System Dynamics Model: Effect on Stakeholders

- Shared understanding of the system within which all stakeholders operate
- Implications for CMS and HRSA regulators and OPTN governance structure regarding potential policy changes
- Major effects on OPO’s and Transplant Programs depending on extent of implemented policy changes
- Greater realization of donor potential, larger volume of transplants, and shorter waiting times for patients awaiting transplants
Questions for Further Research—I

- How will demographic shifts created by changing birth, death, and immigration rates affect patient queues, organ availability, and transplant rates?

- How will changes in the average life expectancy of general population and growing proportion of elderly affect transplant system performance?

- How will an increase in chronic disease incidence rates affect system performance, both in terms of requirements for transplantation and availability of organs from deceased donors?

- How will better care of waitlisted patients, that increases their life expectancy, affect requirements for transplants and outcomes?
Questions for Further Research--II

- How will better support of end-stage patients (who are not yet on waiting lists) affect system performance if it extends their life expectancy? What would be the effect of longer life expectancy for these patients have in combination with easier access to transplant waiting lists?

- How will improvements in scheduling and other decision mechanisms regarding patients waitlisted for transplant affect system performance?

- How will expansions of OPO and transplant program capacity affect system performance, when done in combination with other interventions?

- The work so far has focused on kidney transplantation. How will model results be affected if other organs are included in the model?
Toward Future Action and Performance Improvement

- **Question to Consider:** *How will the results of this study help transplant professionals to better understand what is happening in their donation service area (DSA)? How will assist with moving from potential to actual donors?*

- We hope that our study’s trans-disciplinary approaches will yield powerful, easily accessible information for better general understanding of donation potential through variations in demographic and social characteristics, community infrastructure, and health of the population by geography and other relevant criteria of interest.
Center for Transplant System Excellence

Improving the care continuum
Questions