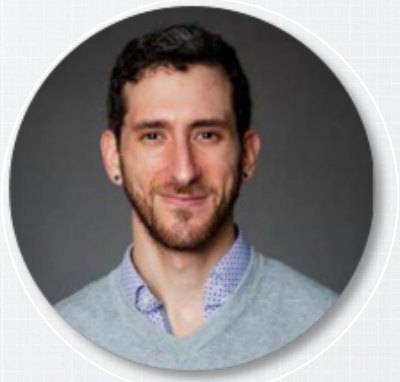
# Improving Access to Transplant Care for Communities of Color

## TODAY'S PANELISTS

**Winfred Williams**
MD
Associate Chief, Nephrology
Massachusetts General Hospital



**Brendan Parent**
JD
Director, Transplant Ethics
NYU School of Medicine

**Erin Paquette**
MD, JD
Assistant Professor, Pediatrics
Ann & Robert H. Lurie Children's Hospital of Chicago

THE Alliance | *Leadership & Engaged Learning in Organ Donation & Transplantation*

**Tuesday, February 22, 2022, 3:00pm – 4:00pm ET**

# Continuing Education Information

## Evaluations & Certificates

### Nursing

The Organ Donation and Transplantation Alliance is offering **1.0 hours of continuing education credit** for this offering, approved by The California Board of Registered Nursing, Provider Number CEP17117. No partial credits will be awarded. CE credit will be issued upon request within 30 days post-webinar.

### CEPTC

The Organ Donation and Transplantation Alliance will be offering **1.0 Category I CEPTC credits** from the American Board for Transplant Certification. Certified clinical transplant and procurement coordinators and certified clinical transplant nurses seeking CEPTC credit must complete the evaluation form within 30 days of the event.

### Certificate of Attendance

Participants desiring CE's that are not being offered, should complete a certificate of attendance.

- Certificates should be claimed within 30 days of this webinar.
- We highly encourage you to provide us with your feedback through completion of the online evaluation tool.
- Detailed instructions will be emailed to you within the next 24 hours.
- You will receive a certificate via email upon completion of a certificate request or an evaluation
- Group leaders, please share the follow-up email with all group participants who attended the webinar.

**Deanna Fenton**
Program Manager
THE Alliance

## Need Assistance?

Contact Us via Zoom Chat, or
info@organdonationalliance.org
786-866-8730

# Meet Our Moderator

**Talia Giordano** MSW, LCSW
Director, Family Services and Caregiver Lifeline Program
GIFT of LIFE Family House

# Meet Our Panelists

## Winfred Williams

MD

Associate Chief of Nephrology; Founding Director, Center for Diversity & Inclusion

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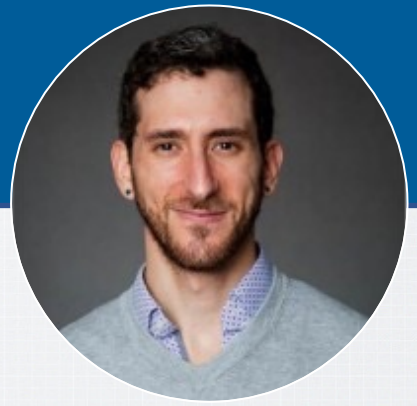

## Brendan Parent

JD

Director, Transplant Ethics & Policy Research

NYU Grossman School of Medicine

## Erin D. Paquette

MD, JD, MBE

Assistant Professor of Pediatrics (Critical Care)

Ann & Robert H. Lurie Children's Hospital of Chicago

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# Achieving Health Equity in Renal Disease: Transplantation as a Model


Winfred W. Williams, MD

Associate Chief, Division of Nephrology

Massachusetts General Hospital

Associate Professor of Medicine

Harvard Medical School


HARVARD MEDICAL SCHOOL
*Teaching Affiliate*

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# Disclosures

None related to this presentation

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# From Health Disparities to Health Equity

## Health Disparities:

"…**preventable** differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations"[1]

## Health Equity:

"When **every person has the opportunity to 'attain his or her full health potential'** and no one is 'disadvantaged from achieving this potential because of social position or other socially determined circumstances"[2]


1. Community Health and Program Services (CHAPS): Health Disparities Among Racial/Ethnic Populations. U.S. Department of Health and Human Services; 2008.
2. Whitehead M, Dahlgren G. Levelling Up (Part 1): A Discussion Paper on Concepts and Principles for Tackling Social Inequities in Health. World Health Organization. Available at http://www.euro.who.int/document/ e89383.pdf.


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# Objectives

- Describe the nature of disparities in transplantation in the U.S.
- Identify factors that are driving disparities in transplantation - using kidney transplantation as a case study
- Highlight examples of multi-level strategies to address disparities in transplantation

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# Why is this topic important?

- The impetus for this is a renewed effort– in the aftermath of a racial reckoning over the past year and broad public outcry-- to address systemic racism in Society and Medicine; and so-called racialized medicine that may result in clinical constructs that do harm to communities of color

# NATURE OF DISPARITIES IN RENAL DISEASE IN THE U.S.

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# CKD in African Americans – epidemiology

- Overall incidence of ESRD in AA is 3.5 – 5 times that of Caucasians and AA constitute about 35 -45% of the dialysis population
- Non-diabetic kidney disease afflicts Black patients disproportionately
- In one study, the rate of nephropathy associated with HIV infection among Black patients was 50 times that of white patients

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# Health Disparities in Renal Disease

- Of more than 500,000 individuals with ESRD in the United States, approximately one third are black

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# Unmet Goals for CKD Care in African Americans

AA CKD patients have poorer outcomes with respect to:

- Anemia
- HTN control
- Timely nephrology referral
- Dialysis fistula or AV graft placement
- Adequate dialysis treatment, and
- Access to Transplant

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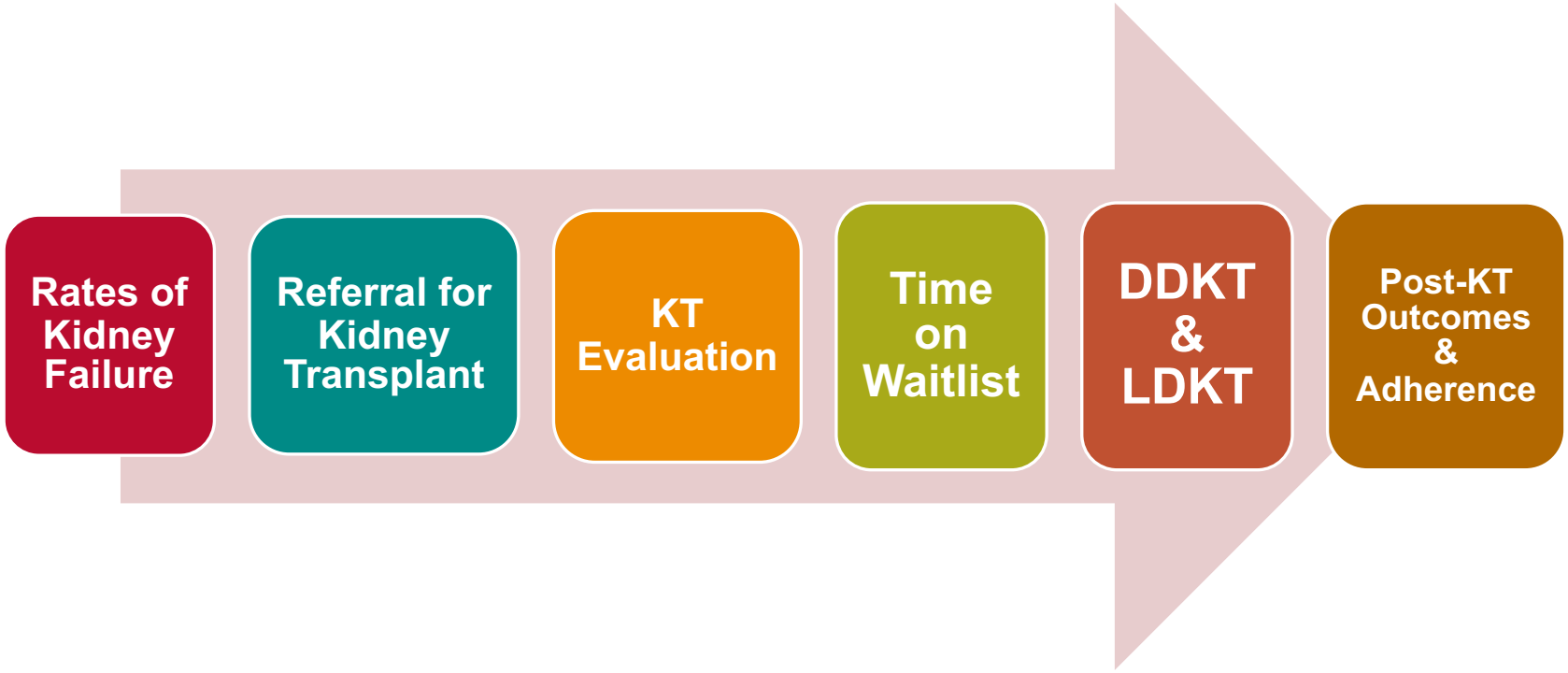
# Case Study: Disparities Across the Kidney Transplant Trajectory




Slide by Larissa Myaskovsky, 2015

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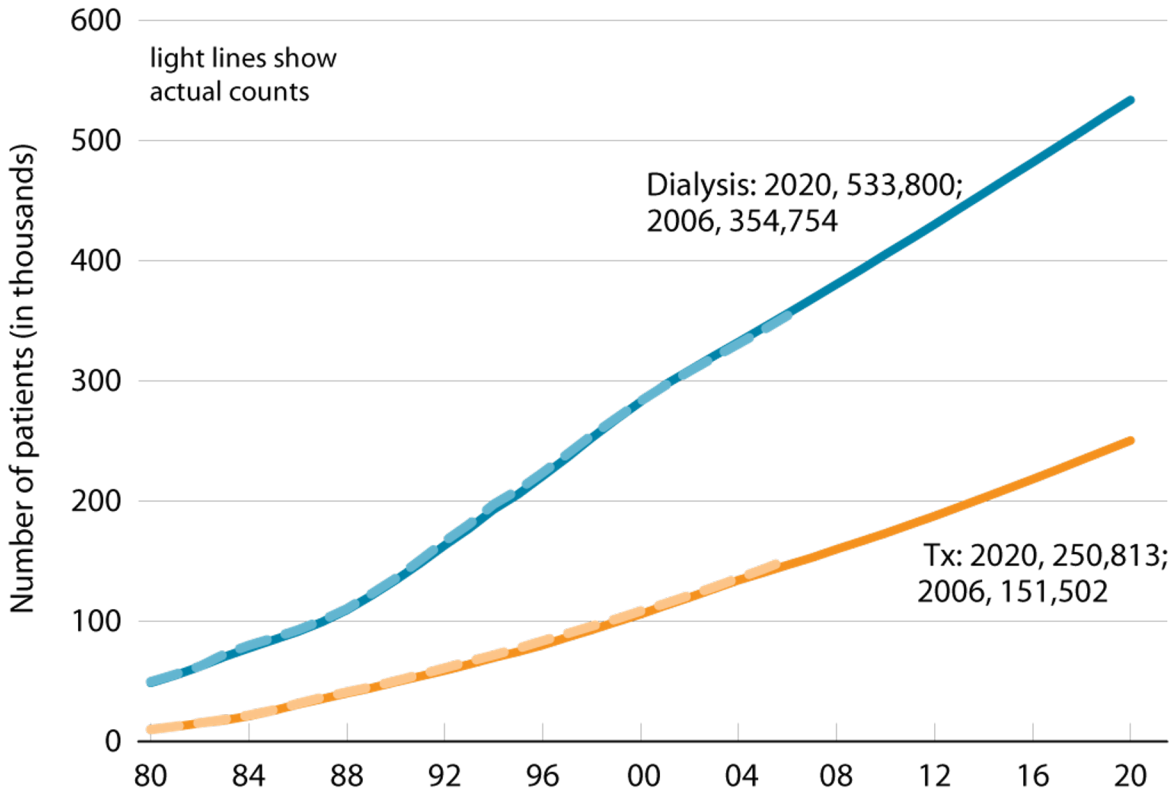
# Projected growth of prevalent dialysis & transplants populations

Figure 2.2 (Volume 2)




**counts projected using a Markov model. Original projections used data through 2000; new projections use data through 2006.**

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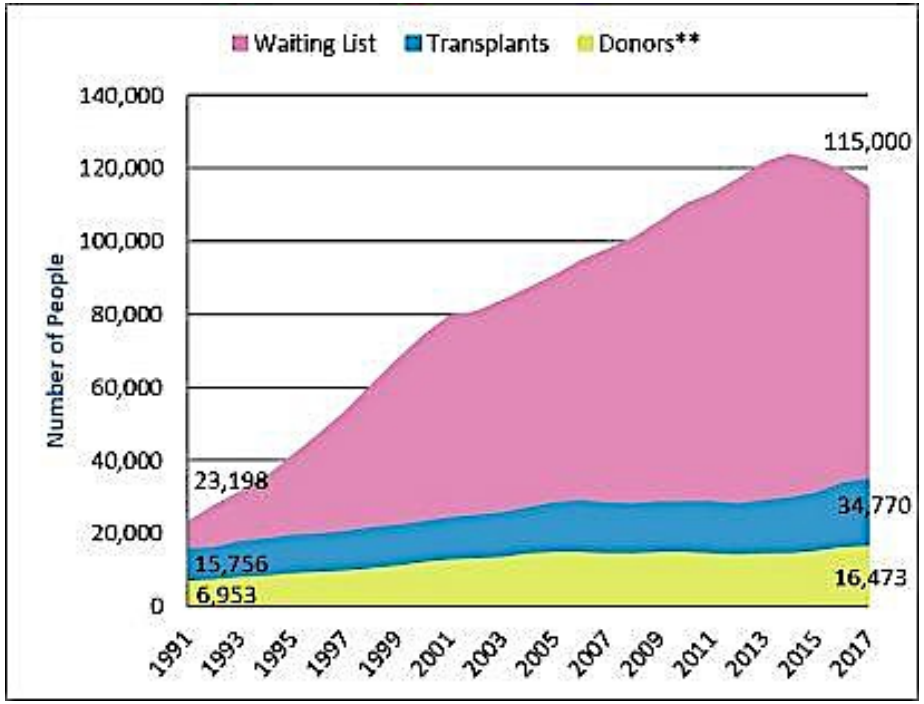
# Actual Conditions for Allocation

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# Actual Conditions for Allocation

Demand > Supply

*Our challenge is to allocate a resource where demand greatly exceeds supply – this means we need to make trade-offs based on values and guiding principles*

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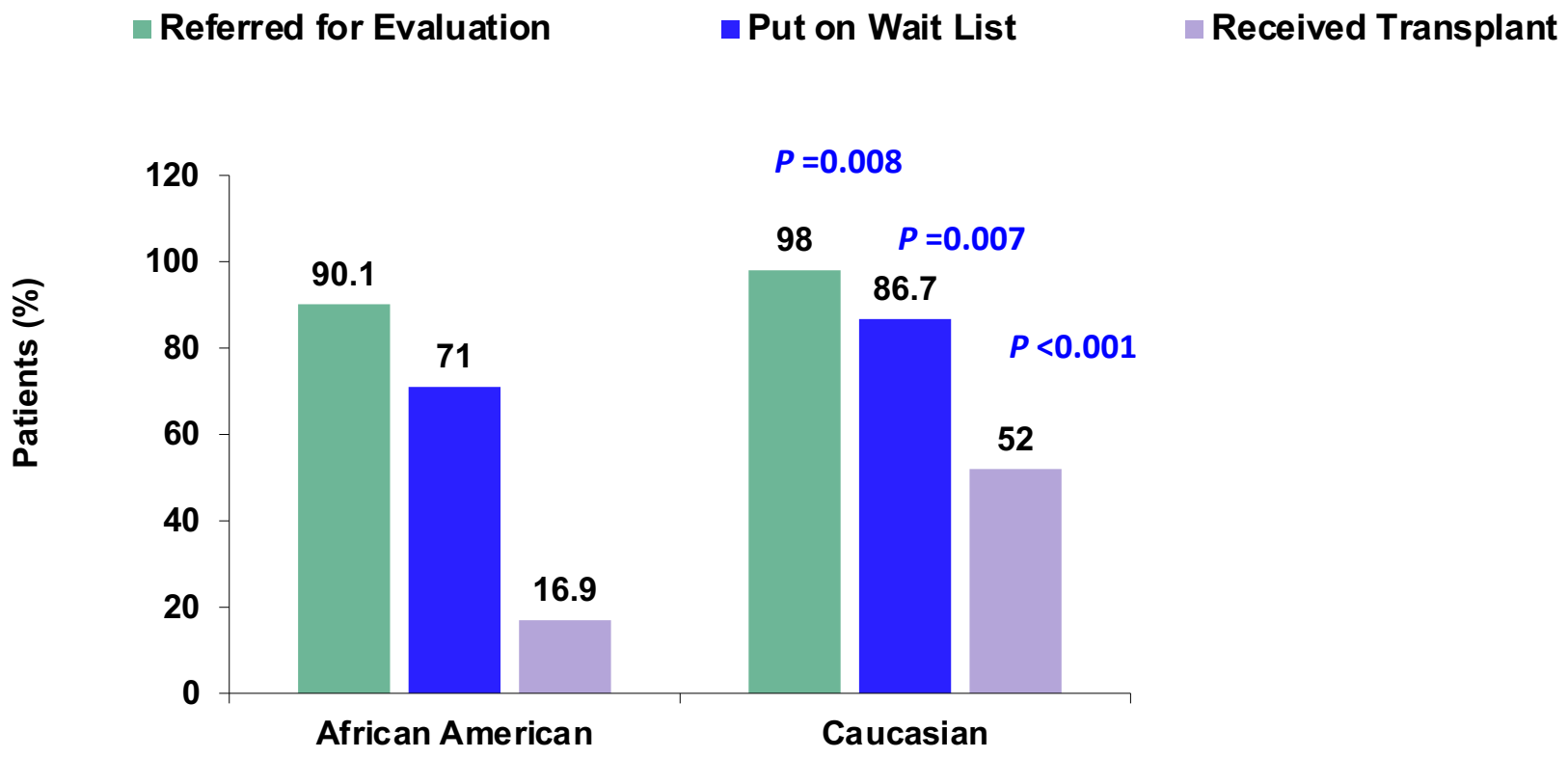
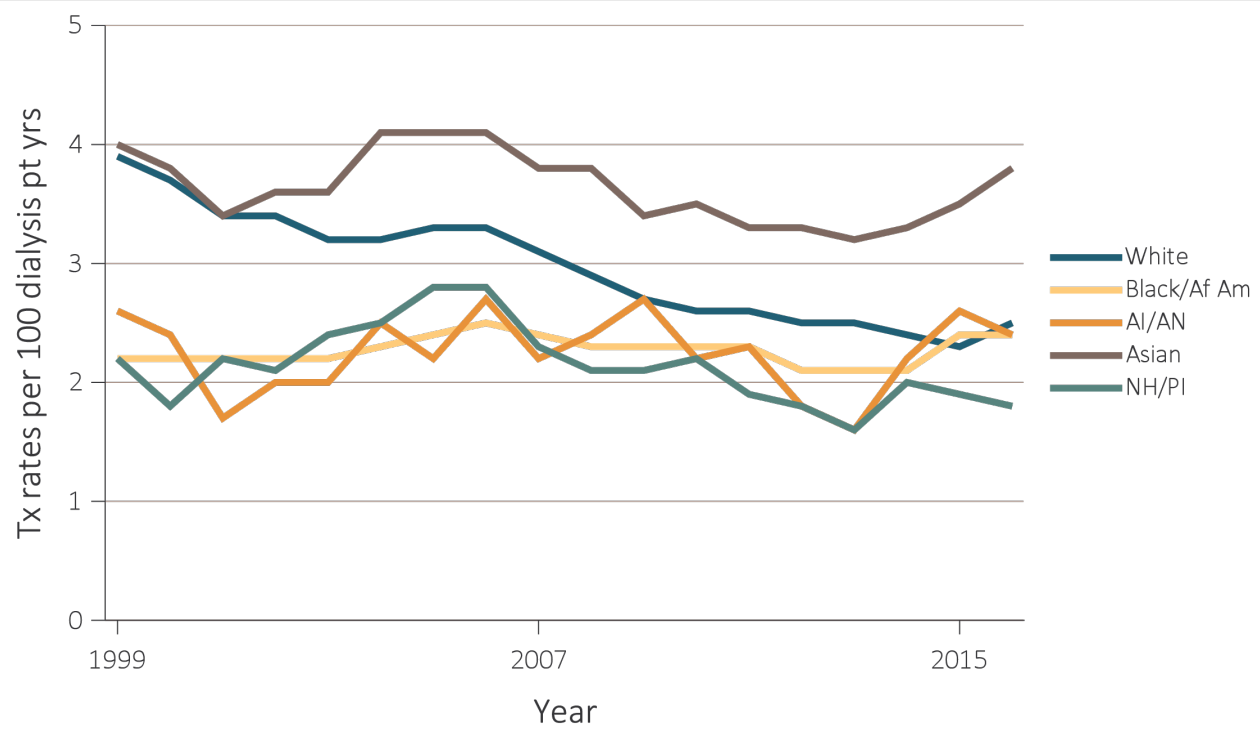
# Ethnic Disparities in Access to Transplantation




Epstein AM, Ayanian JZ, Keogh JH, et al. *N Engl J Med*. 2000;343:1537-1544.

# Deceased Donor Kidney Transplant Rates, 1999-2016




USRDS 2018 Annual Data Report , Volume 2 ESRD, Chapter

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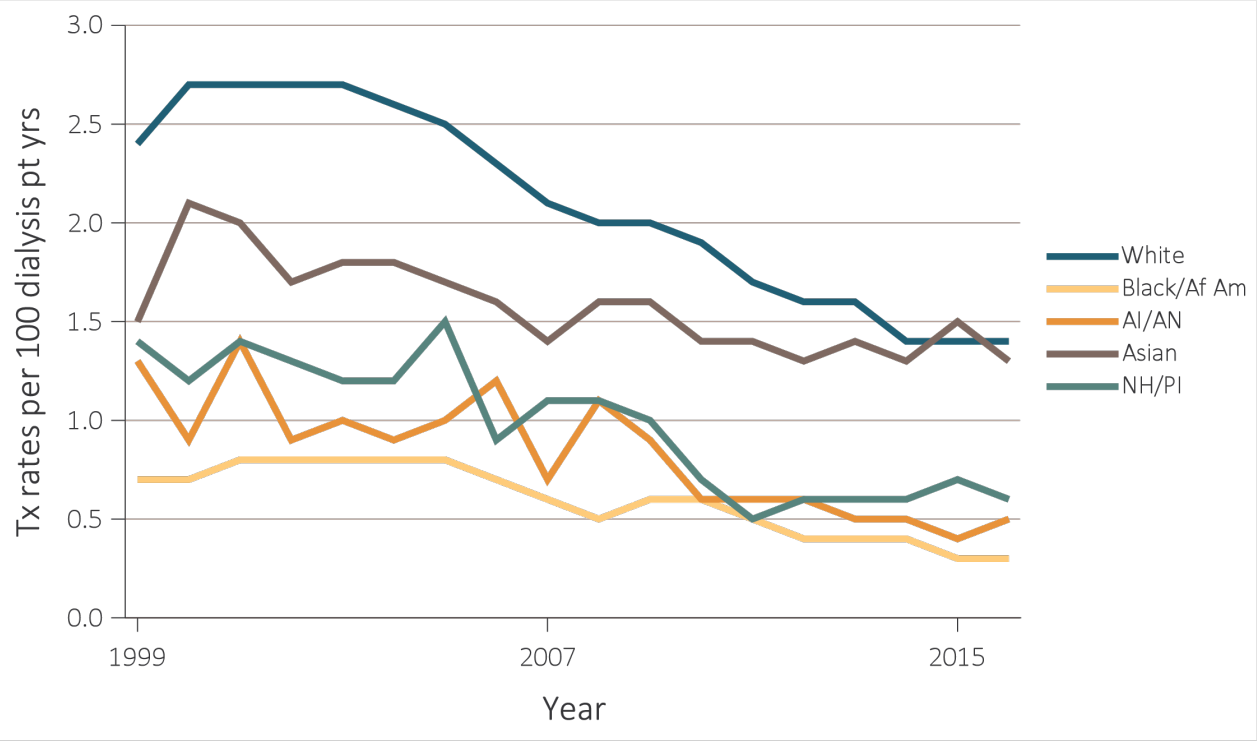
# Living Donor Kidney Transplant Rates, 1999-2016




USRDS 2018 Annual Data Report , Volume 2 ESRD, Chapter 6

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# FACTORS INFLUENCING DISPARITIES IN KIDNEY TRANSPLANTATION

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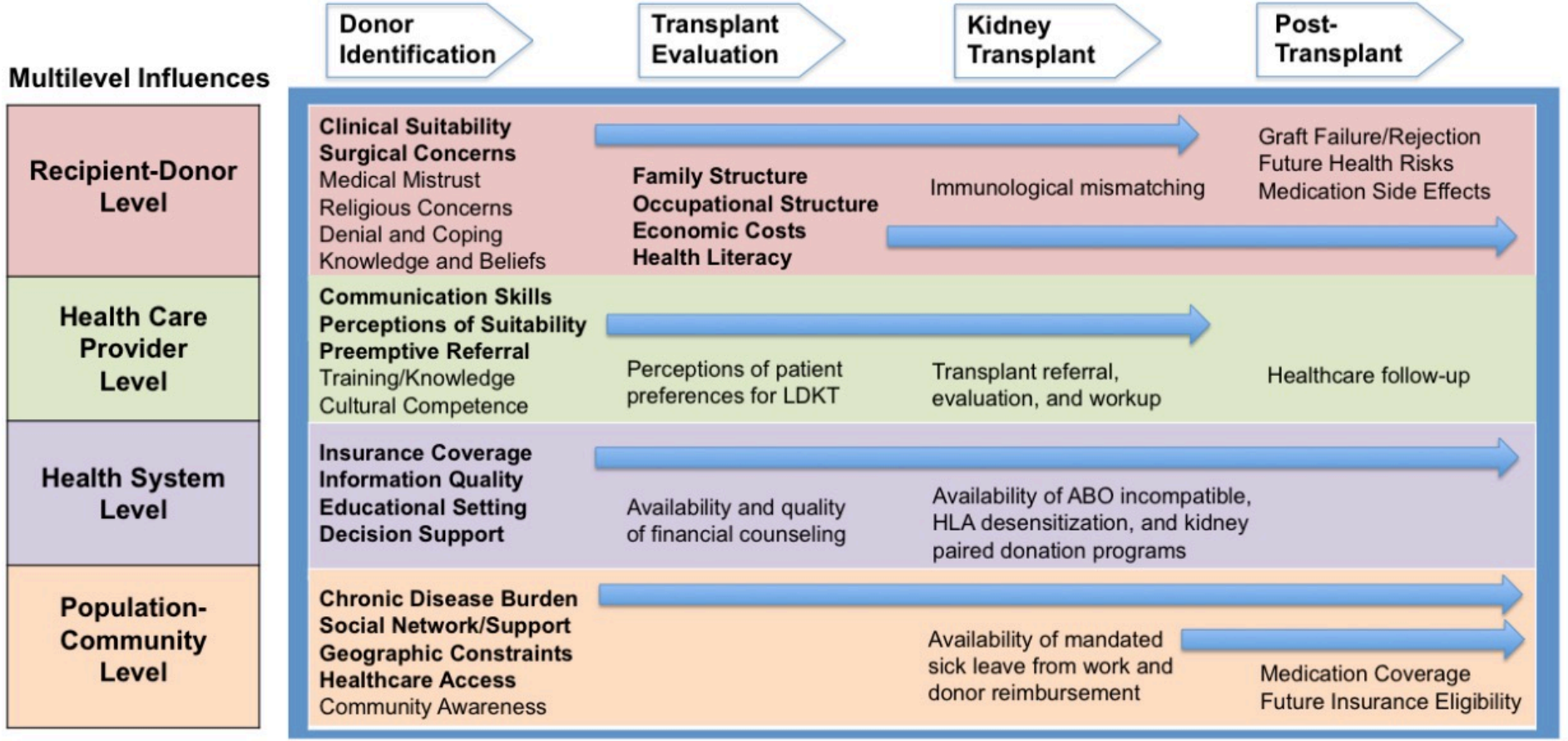
# Multilevel Barriers to Donation and Transplant




Source: Purnell TS, Hall YN, Boulware LE. Understanding and Overcoming Barriers to Living Kidney Donation among Racial and Ethnic Minorities in the United States. *Advances in Chronic Kidney Disease.* 2012 Jul; 19(4): 244-51.

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Clin J Am Soc Nephrol. 2012 Sep 7; 7(9): 1490–1497. PMCID: PMC3430955
Published online 2012 Jul 26. doi: 10.2215/CJN.13151211

# Association of Race and Insurance Type with Delayed Assessment for Kidney Transplantation among Patients Initiating Dialysis in the United States

Kirsten L. Johansen,[*†] Rebecca Zhang,[*] Yijian Huang,[*] Rachel E. Patzer,[‡] and Nancy G. Kutner[*]

## Table 3.

Odds ratios for being reported not assessed for transplantation

| | Age (years) | | | | | |
|---|---|---|---|---|---|---|
| | All Ages (*n*=355,738) | ≤18 to <35 (*n*=16,794) | 35 to <50 (*n*=49,402) | 50 to <65 (*n*=111,280) | 65 to <80 (*n*=124,842) | ≥80 (*n*=43,420) |
| Black race | 1.05 (1.02, 1.07) | 1.27 (1.13, 1.43) | 1.02 (0.96, 1.09) | 1.00 (0.97, 1.04) | 1.02 (0.98, 1.06) | 0.99 (0.91, 1.08) |

Young black patients much less likely to be presented option of transplantation around time of starting dialysis.

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# Kidney Allocation Policy in the U.S

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# Kidney Allocation in the U.S.

## Prior System Limitations

### "360" Review of U.S. Kidney Allocation - 2003 to 2013

- Mismatch in graft/patient survival – Longevity mismatches
- High discard rates
- Biological and ethnic inequities
- Fragmented, non-unified system

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# Primary Policy Objectives

- Make the most of every donated kidney without diminishing access
- Promote graft survival for those at highest risk of retransplant
- Minimize loss of potential graft function through better longevity matching
- Improve efficiency and utilization by providing better information about kidney offers

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# Primary Policy Objectives

- Provide comprehensive data to guide transplant decision making

- Reduce differences in access for ethnic minorities and sensitized candidates

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# What changed with KAS?

"New," *Kidney Allocation System* ("KAS")

- What changed on December 4, 2014, and why?
- What has been the impact of KAS…

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# System Design

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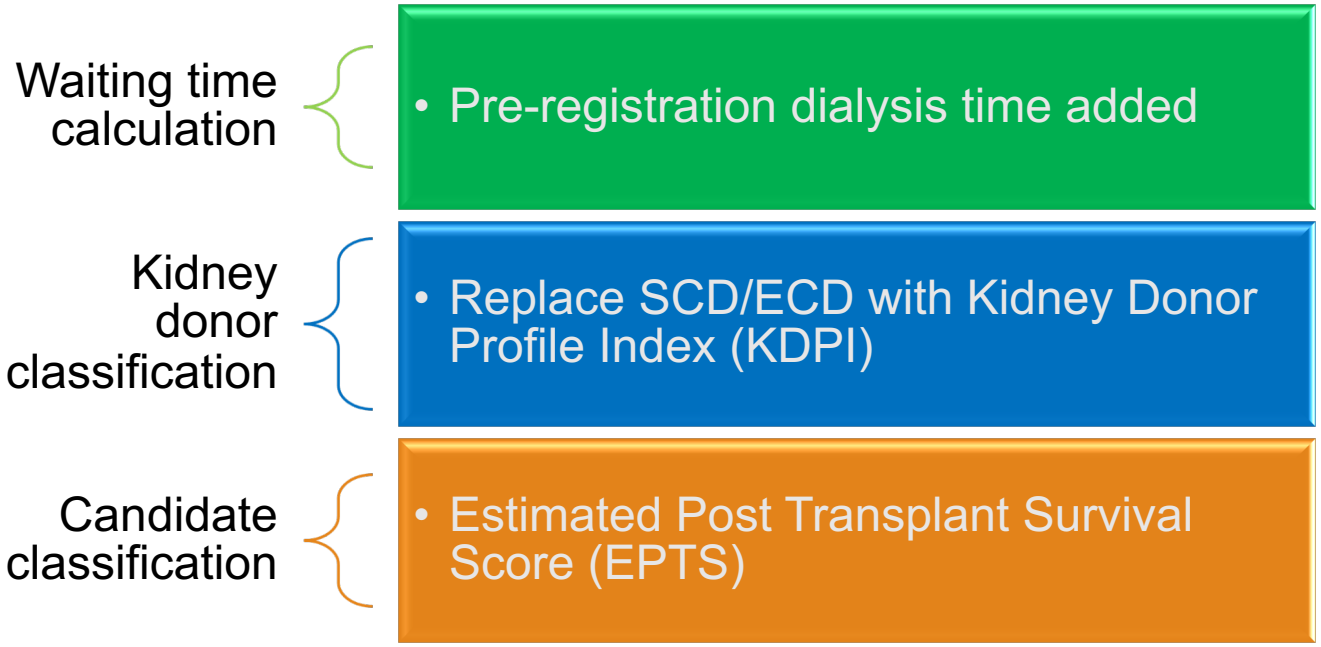
# Key Allocation Component Changes of KAS

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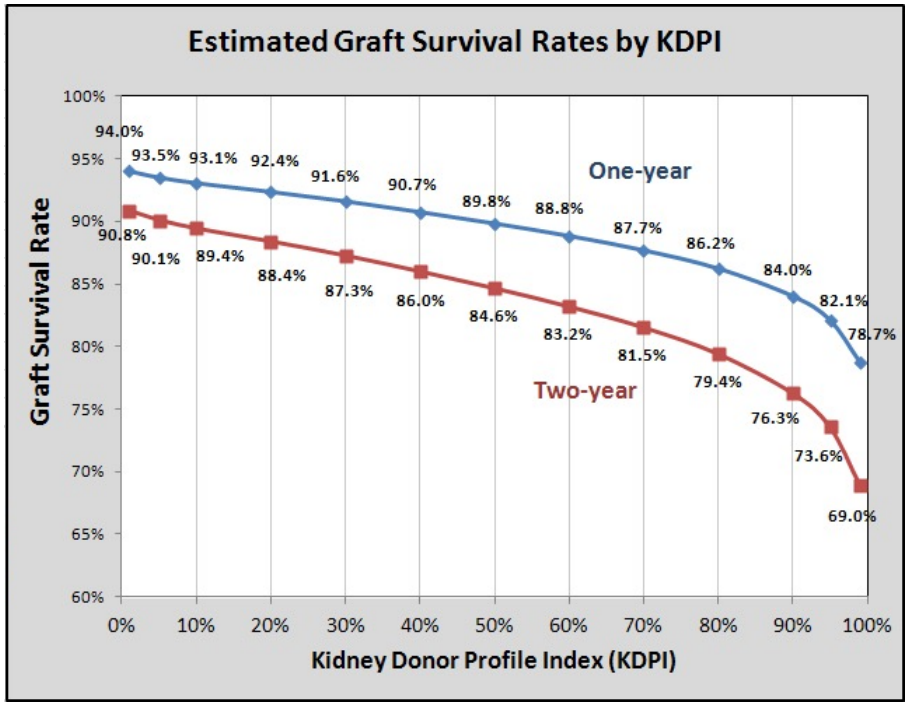
# Kidney Donor Profile Index (KDPI)

KDPI Variables

- Donor age
- Height
- Weight
- Ethnicity
- History of Hypertension
- History of Diabetes
- Cause of Death
- Serum Creatinine




*KDPI values now displayed with all organ offers in DonorNet®*

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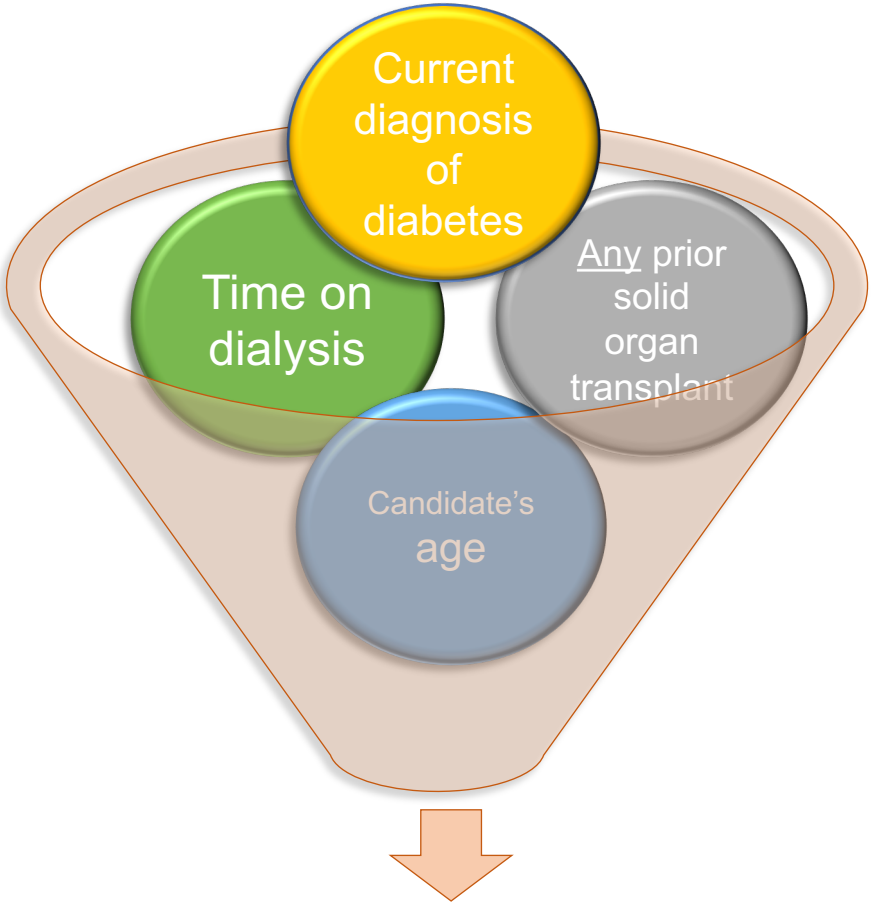
# Estimated Post Transplant Survival (EPTS)




EPTS score range 0%-100%

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# EPTS & KDPI in the New System

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# *For both KDPI and EPTS, lower score is better!*

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# Key Allocation Component Changes of KAS

| | |
|---|---|
| Blood type eligibility | • $A_2$ and $A_2B$ to B compatible |
| Regional high KDPI distribution | • KDPI>85% kidneys allocated to combined local + regional list |
| Priority for sensitized candidates | • CPRA sliding scale and regional/national sharing for CPRA >98% |

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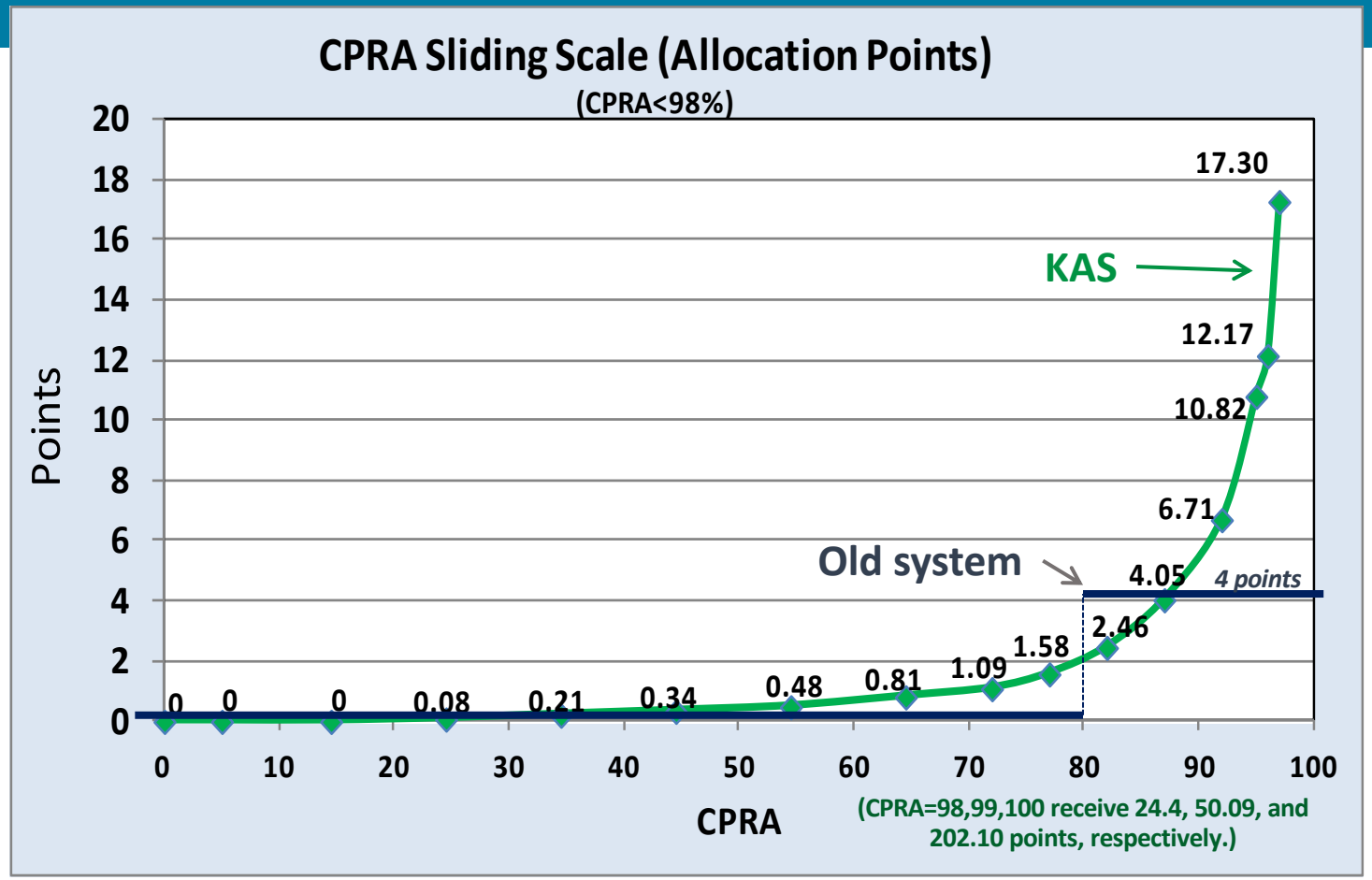


*Stewart*
*ATC 2012*

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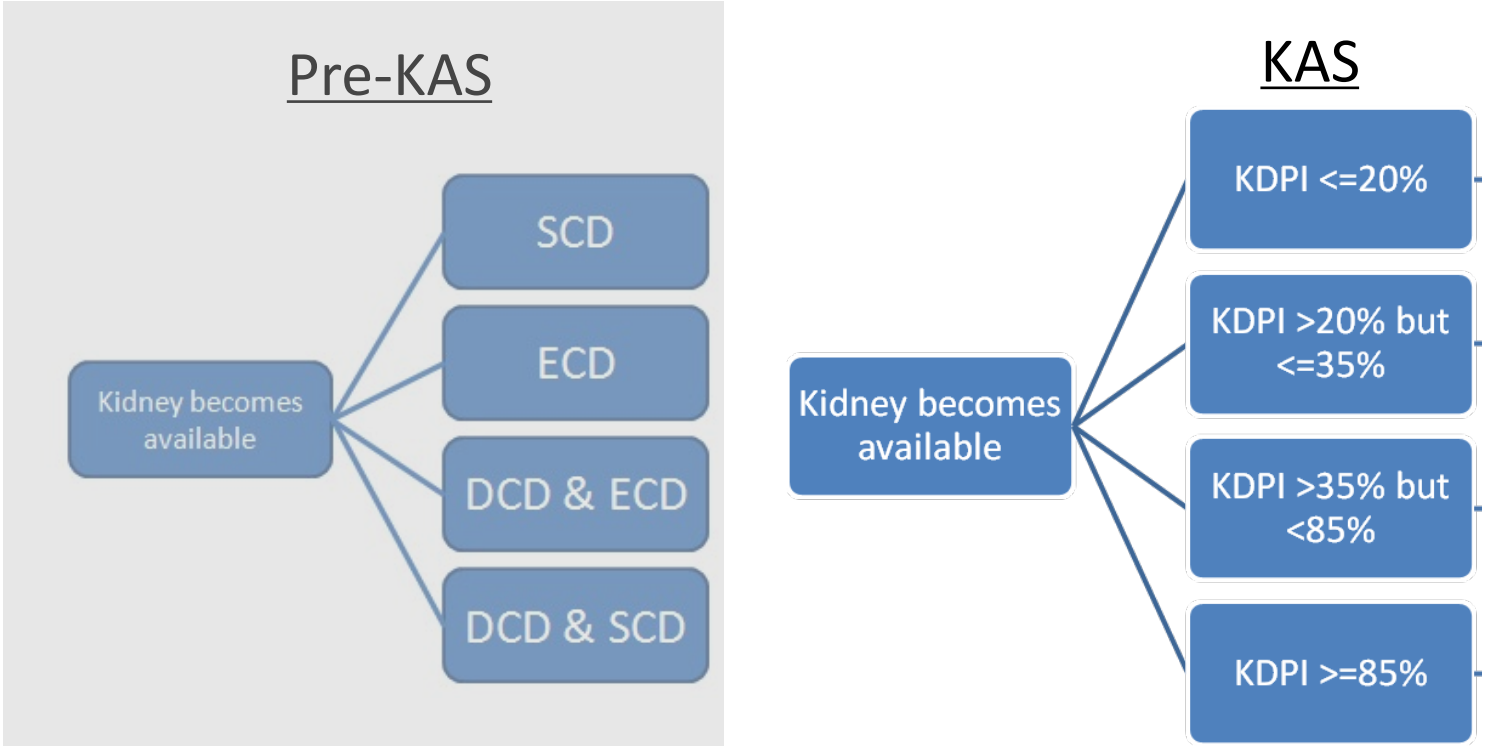
# Overview of New System




*All allocation sequences to be based on KDPI*

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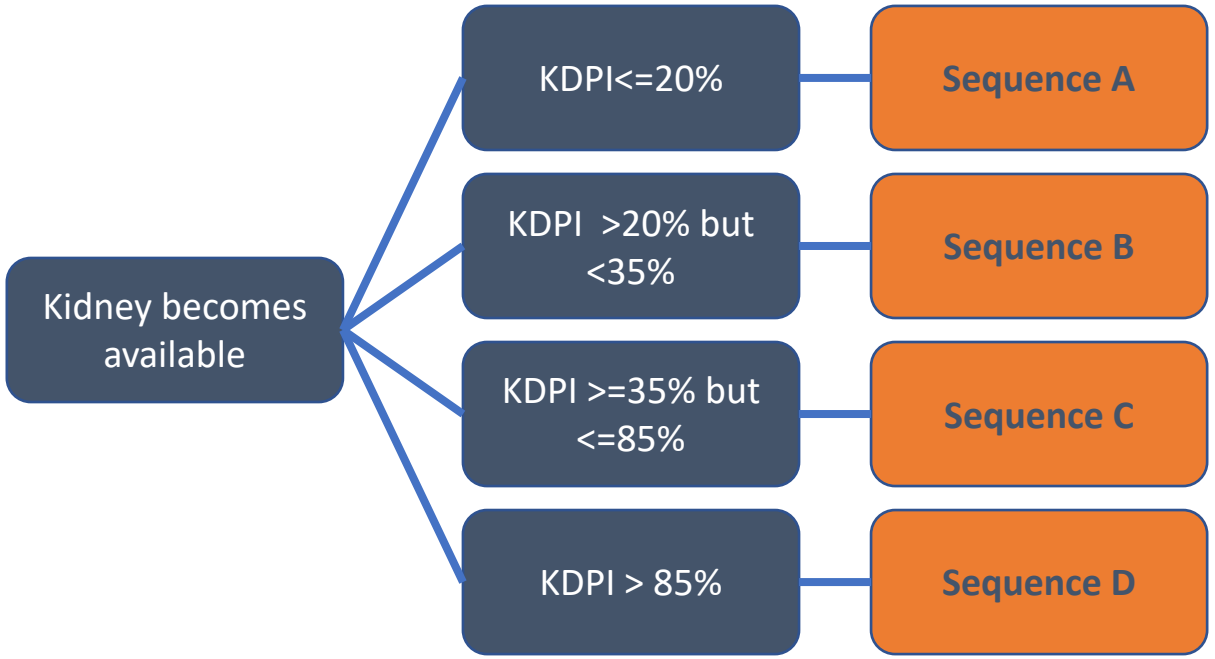
# Sequences based on KDPI

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# Sequences based on KDPI

**Sequence A**
**KDPI<=20%**

**Sequence B**
**KDPI >20% but <35%**

**Sequence C**
**KDPI>=35% but <=85%**

**Sequence D**
**KDPI>85%**

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| **Sequence A**<br>**KDPI <=20%** | **Sequence B**<br>**KDPI >20% but <35%** | **Sequence C**<br>**KDPI >=35% but <=85%** | **Sequence D**<br>**KDPI>85%** |
|---|---|---|---|
| Highly Sensitized<br>0-ABDRmm (top 20% EPTS)<br>Prior living donor<br>Local pediatrics<br>Local top 20% EPTS<br>0-ABDRmm (all)<br>Local (all)<br>Regional pediatrics<br>Regional (top 20%)<br>Regional (all)<br>National pediatrics<br>National (top 20%)<br>National (all) | Highly Sensitized<br>0-ABDRmm<br>Prior living donor<br>Local pediatrics<br>Local adults<br>Regional pediatrics<br>Regional adults<br>National pediatrics<br>National adults | Highly Sensitized<br>0-ABDRmm<br>Prior living donor<br>Local<br>Regional<br>National | Highly Sensitized<br>0-ABDRmm<br>Local + Regional<br>National<br>**all categories in Sequence D are limited to adult candidates* |

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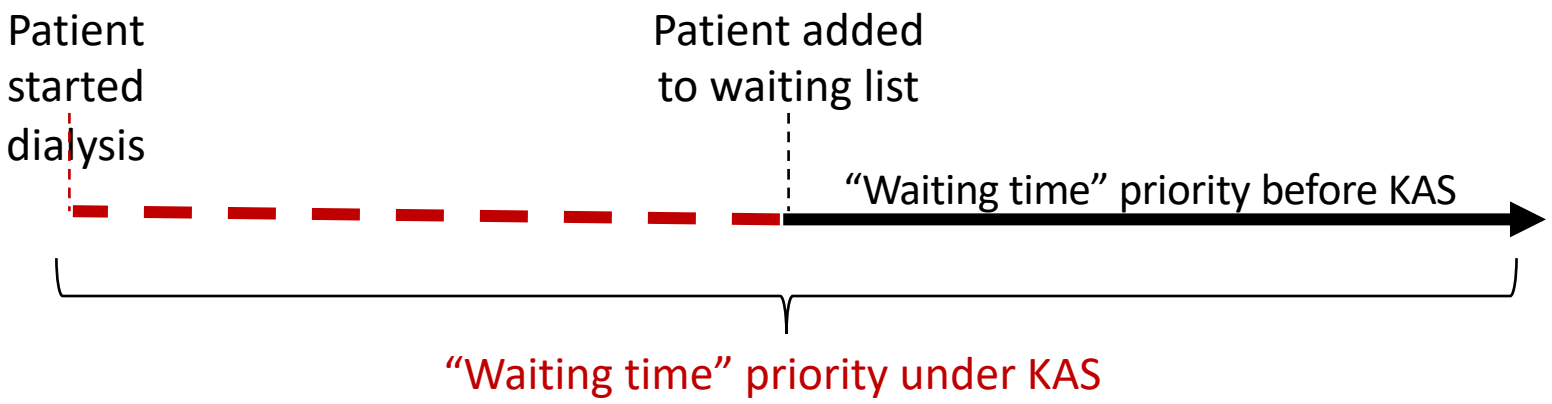
# KAS gives credit for pre-listing dialysis time

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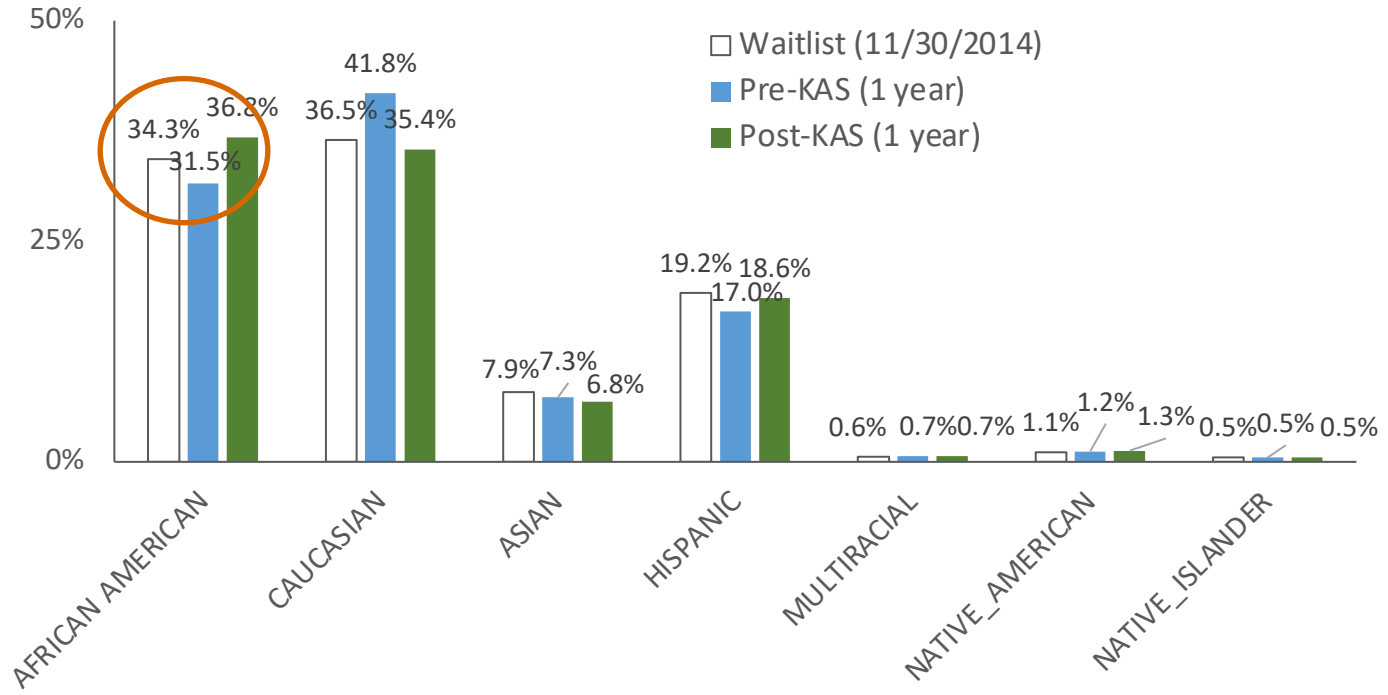
# Kidney Transplants by Race/Ethnicity

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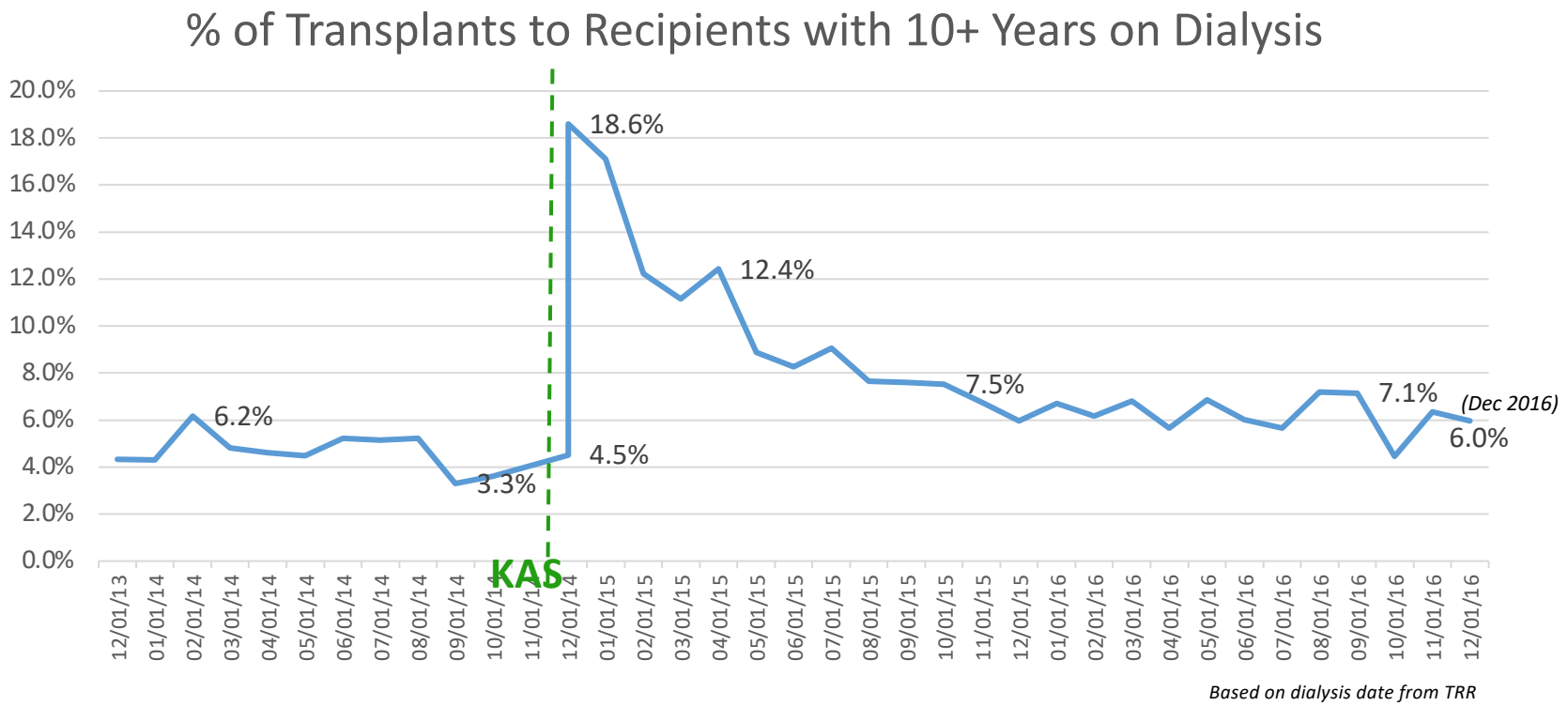
# High dialysis time recipient “bolus effect”




- After KAS, the % of transplants to recipients with 10+ years of dialysis rose sharply to nearly 19% but has tapered to about 6% nationally.

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# MULTI-LEVEL STRATEGIES TO ADDRESS DISPARITIES IN TRANSPLANTATION

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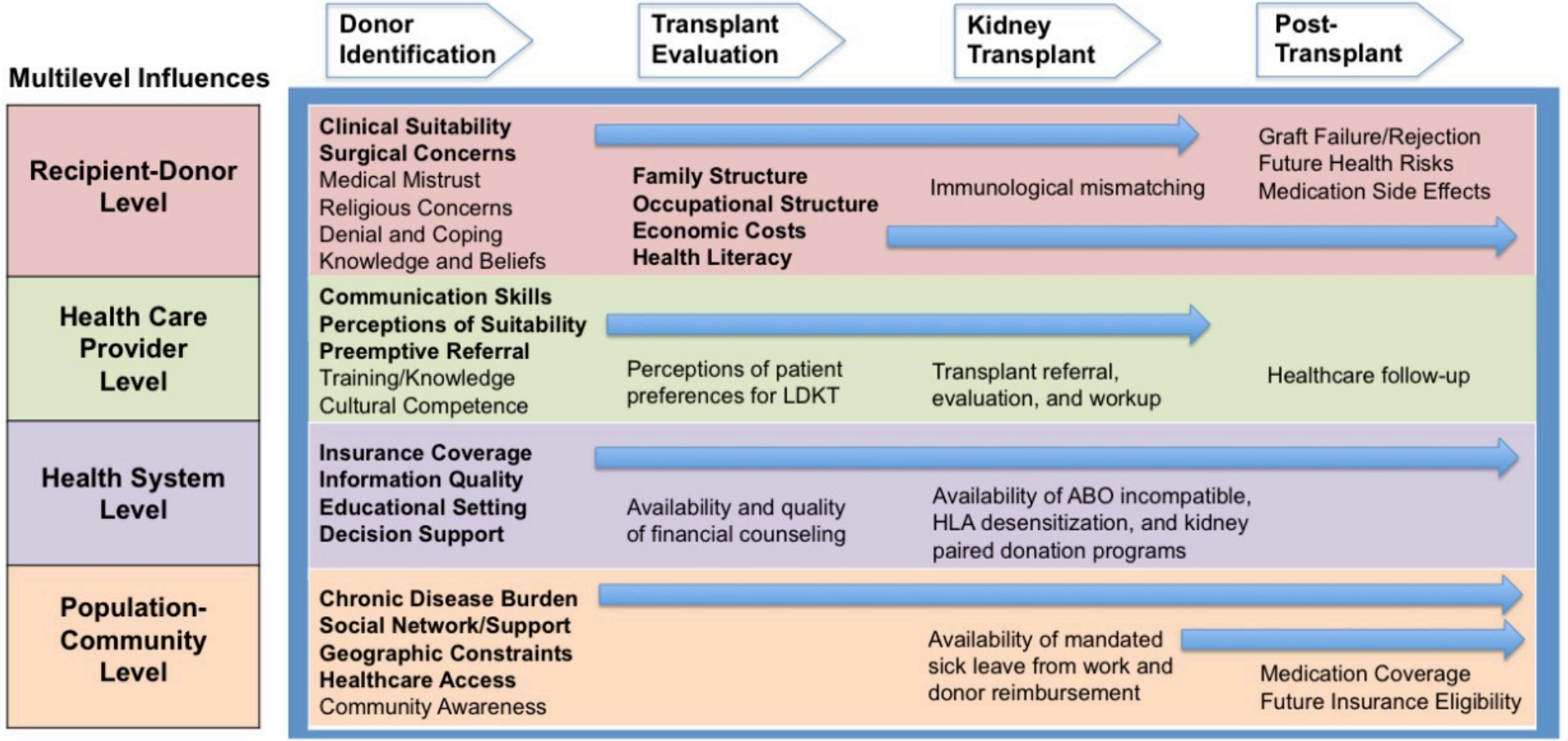
# Multilevel Barriers to Donation and Transplant




Source: Purnell TS, Hall YN, Boulware LE. Understanding and Overcoming Barriers to Living Kidney Donation among Racial and Ethnic Minorities in the United States. *Advances in Chronic Kidney Disease.* 2012 Jul; 19(4): 244-51.

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# New Challenges

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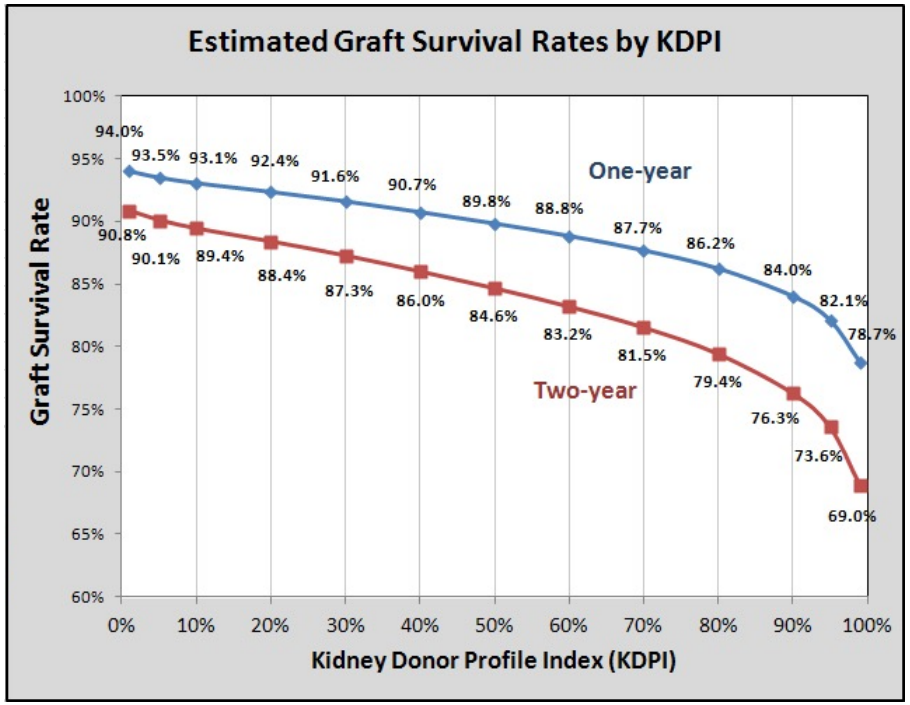
# Revisiting KDPI

KDPI Variables

- Donor age
- Height
- Weight
- Ethnicity
- History of Hypertension
- History of Diabetes
- Cause of Death
- Serum Creatinine




*KDPI values now displayed with all organ offers in DonorNet®*

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# KDPI Development

- Identification of donor factors important to graft survival was performed using a US cohort of 70,000 adult first-time kidney recipients of a DDKTx between 1995-2005

- Implemented in 02/2012 to increase provider familiarity but not incorporated into actual allocation algorithm until 12/04/2014.

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# KDPI History

- Replaced Standard versus Extended Criteria donors
- Ranges from 0 – 100%, with higher scores representing shorter estimated post-transplant graft survival and lower organ quality
- Based on 10 variables
- Purpose: help longevity matching of deceased donors to candidates who have the best EPTS
- Primarily used to help providers assess the suitability of each organ offer

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# Inclusion of Race in the KDPI

- The inclusion of a “race coefficient” was based on the observation that organs originating from Black donors were associated with a 20% higher graft failure rate.

- These organs would then have a higher KDPI and would more likely be declined or discarded than organs from other ethnic or racial groups

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# Reassessing KDPI: regional variation

- Across OPTN regions-- marked variation in deceased donor ethnicity with some regions having high representation of Black donors; others low (ranging from 12% to 41.5%)

- Because of the higher KDPI of organs from Black donors, regions with higher KDPI organs may have higher odds of organ declines/discards

- This may disadvantage Black WL candidates who may have Abs against common HLAs in the predominantly White donor pool

# Replacing Black Race with genetic variation at APO-L1: effects on KDPI

- Studies of Black donors with high-risk APO-L1 genetic variants have been associated with 2X risk of graft failure in 5-yr f/u
- This may be a function of homozygosity for G1 or G2 or compound heterozygosity for G1/G2.
- Leading some to suggest genotyping and quantifying variant dose; eliminate Black race as a factor
- Such an approach would maintain risk discrimination for graft outcomes but remove the race inflation factor– potentially lowering KDPI in some cases

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# Pre-emptive Listing for Tx

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PERSONAL VIEWPOINT

AJT

# Racial disparities in preemptive waitlisting and deceased donor kidney transplantation: Ethics and solutions

Peter P. Reese[1,2] | Sumit Mohan[3,4] | Kristen L. King[3] | Winfred W. Williams[5] | Vishnu S. Potluri[1] | Meera N. Harhay[6,7,8] | Nwamaka D. Eneanya[1,2]

[1]Department of Medicine, Renal-Electrolyte and Hypertension Division, Perelman School of Medicine, University of Pennsylvania, Philadelphia, Pennsylvania

[2]Department of Biostatistics, Epidemiology and Informatics, University of Pennsylvania, Philadelphia, Pennsylvania

[3]Department of Medicine, Division of Nephrology, Columbia University College of Physicians & Surgeons and New York Presbyterian Hospital, New York, New York

[4]Department of Epidemiology, Mailman School of Public Health, Columbia University, New York, New York

[5]Division of Nephrology, Department of Medicine, Massachusetts General Hospital, Harvard Medical School, Boston, MA

[6]Department of Medicine, Drexel University College of Medicine, Philadelphia, Pennsylvania, USA

[7]Department of Epidemiology and Biostatistics, Drexel University Dornsife School of Public Health, Philadelphia, Pennsylvania

[8]Tower Health Transplant Institute, Tower Health System, West Reading, Pennsylvania

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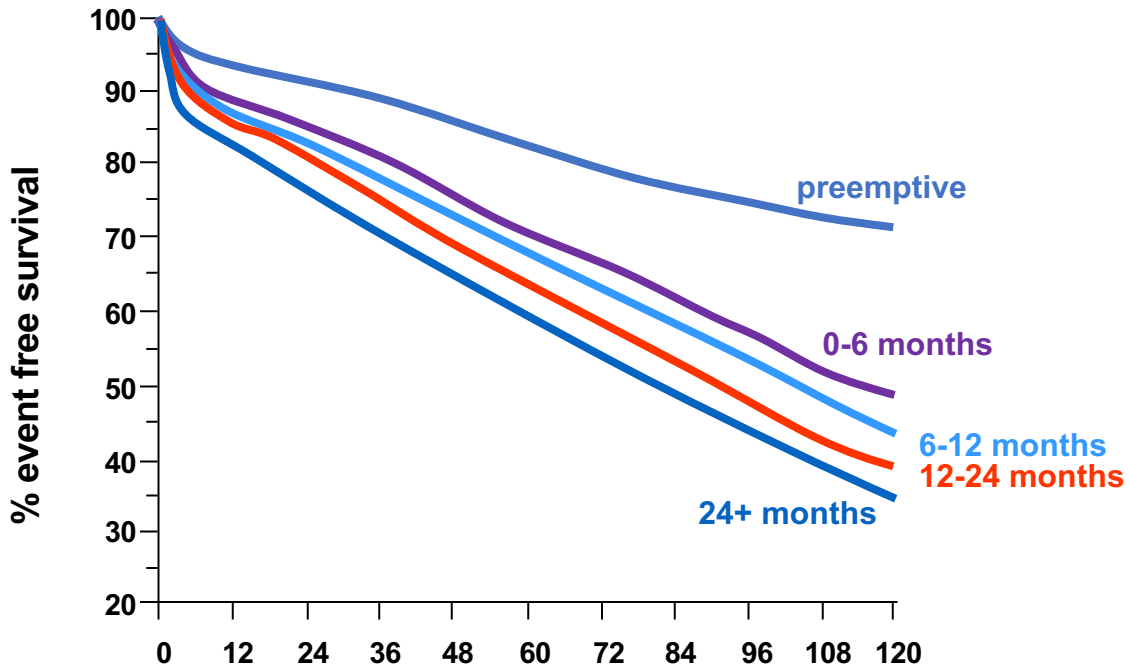
# Advantages of Pre-Emptive Kidney Transplant

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# Unequal Access to Preemptive Kidney Transplantation

- 20 years ago, Kasiske et al. reported that Black patients were much less likely to receive a preemptive kidney transplant than White patients and that “substantial efforts on the part of all who care for patients with kidney disease would be required to correct this inequity.”

- Yet, policy changes to the US kidney allocation system (KAS) that were implemented to mitigate transplant disparities have neglected preemptive kidney transplantation.

Kasiske BL et al. JASN. 2002;13:1358

Jay CL et al.Transplantation. 2016;100: 1120

# Unequal Access to Preemptive Kidney Transplantation

- In 2019, 11% of all adult DDKTxs (1,859) were preemptive
- White patients received 65% and Black patients received only 17% of those preemptive kidneys, during a year when the waiting list comprised 38% White and 31% Black patients
- Fig.1 shows persistent racial disparities in preemptive kidney transplantation over time--

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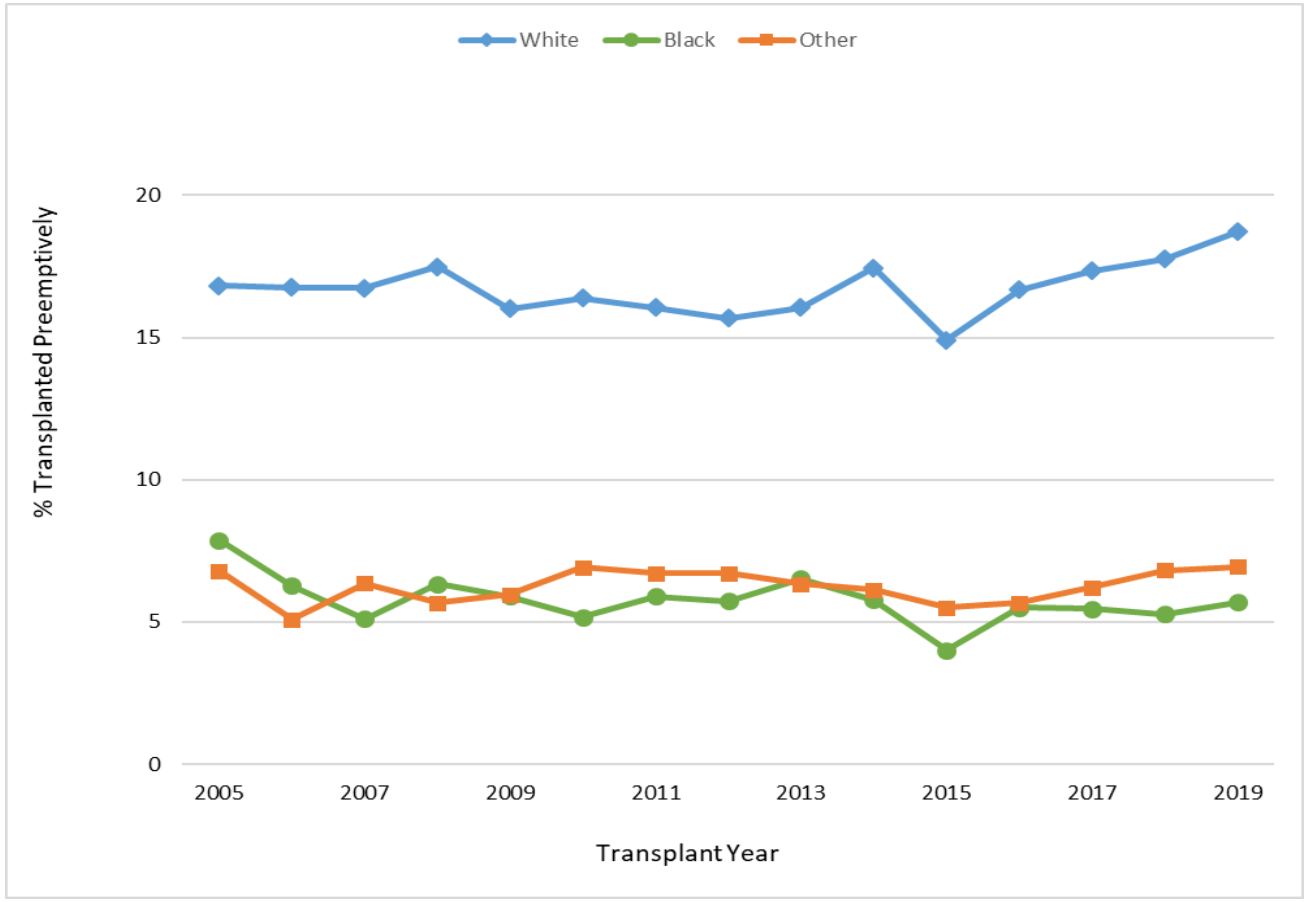
# Racial disparities in preemptive deceased donor kidney transplantation in the US, over time*

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# Unequal Access to Preemptive Kidney Transplantation

- King et al. analyzed national registry data and reported that, compared to White patients, Black patients had an adjusted Odds Ratio of 0.41 (95% CI 0.37, 0.45; $p < .001$) for receiving a preemptive deceased donor kidney transplant since implementation of KAS in 2015 –
- A widening disparity from the adjusted OR of 0.48 prior to KAS

King KL et al. JASN. 2019; 14:1500

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# Unequal Access to Preemptive Kidney Transplantation

- Preemptively waitlisted patients carry forward their allocation priority even after starting dialysis, so the major advantage of timely transplant referral is a key mechanism that facilitates inequities in access to the entire pool of deceased donor kidneys
- Fig. 2 reveals major disparities in preemptive waitlisting over time --
- In 2019, 48% of waitlisted White patients, but only 22% of waitlisted Black patients, began to accrue waiting time priority before dialysis

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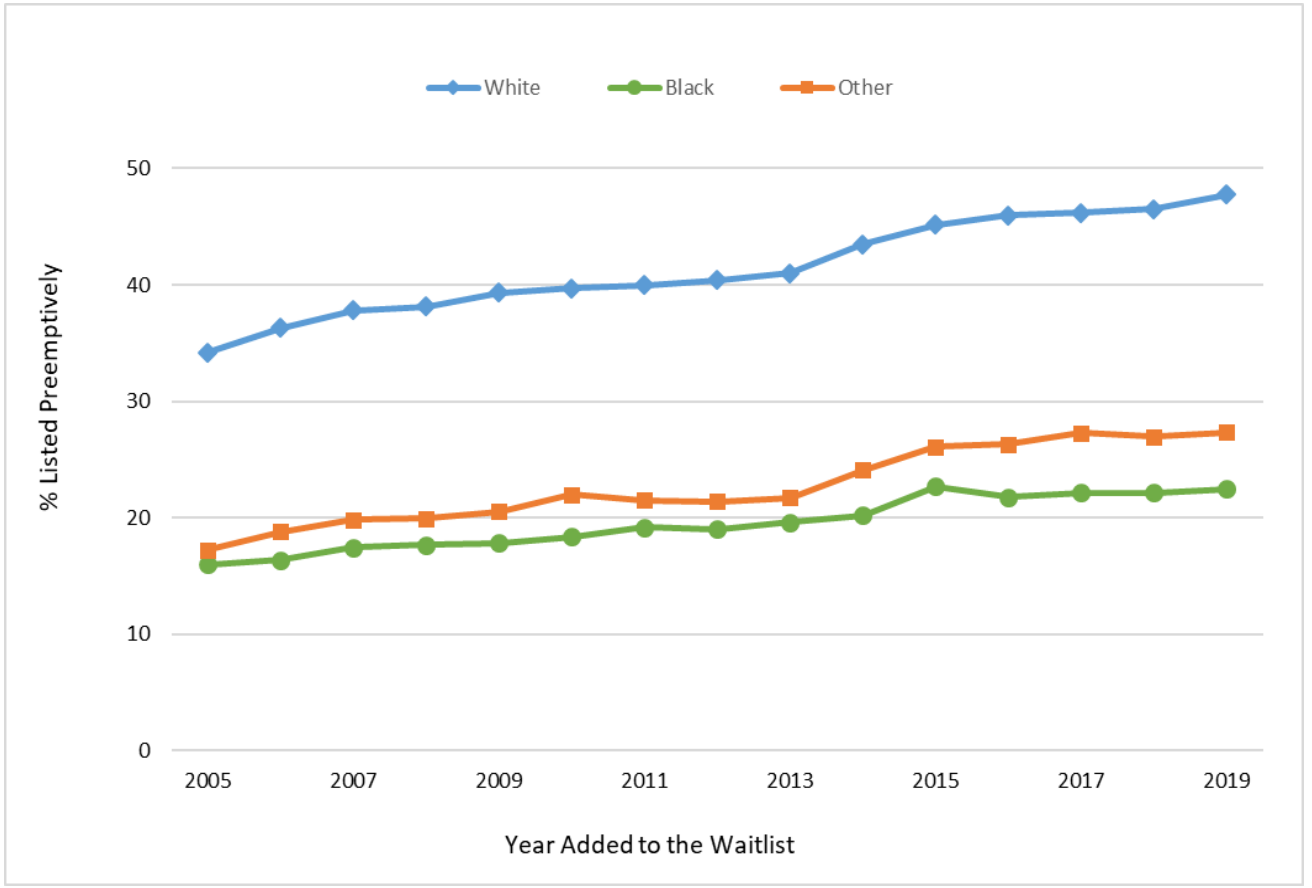
# Racial disparities in preemptive waitlisting for kidney transplantation in the US, over time*

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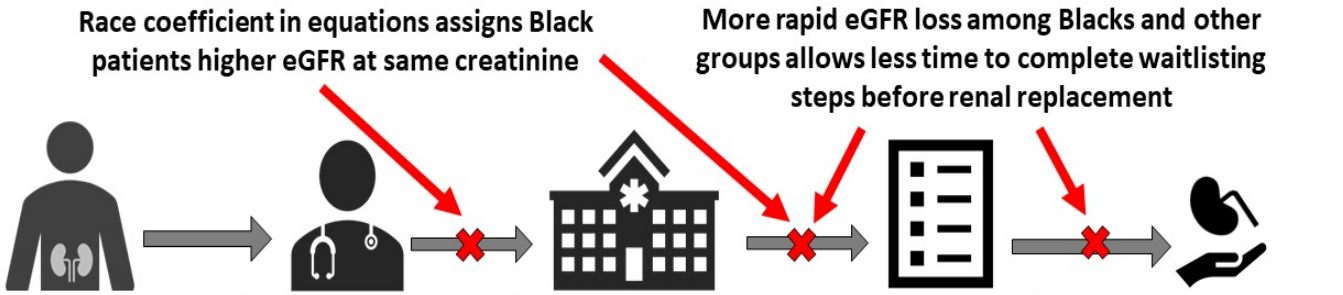
# The diverse barriers to preemptive waitlisting and deceased donor kidney transplantation in the US will require multiple remedies to improve equitable access




| Patient Level Barriers for Individual with CKD | Provider Level Barriers: Nephrologist, Primary Care Doctor | Transplant Center Level Barriers | Barriers to Pre-emptive Waitlisting | Barriers to Pre-emptive Transplantation |
|---|---|---|---|---|
| Limited education and resources to navigate health care system | Limited provider availability | Insurance barriers to transplant center access | Lack of standardization in requirement for eGFR <20 ml/min to gain allocation priority | First-come, first-served allocation system favoring patients waitlisted prior to dialysis |
| Low health literacy related to CKD and urgency in transplant evaluation | Lack of understanding of urgency in transplant referral | Lengthy transplant evaluation and counseling process | Center disincentives to rapid waitlisting: financial, admin burdens | |
| No insurance or restricted access to providers | Clinician and structural racism; Lack of accommodation for challenges faced by minority patients | | | |
| Lack of trust in health system | | | | |

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# SUMMARY

- GFR equations use Black race to achieve slightly better statistical precision in estimating kidney function on the population level

- The net effect is that compared to White patients with the same age, sex, and serum creatinine, Black patients are estimated to have a higher eGFR using the old (2009 and 2012) CKD-Epi and MDRD equations

- This may negatively affect timely referral patterns for ethnic minorities seeking kidney replacement services, such as referral to and evaluation for kidney transplantation

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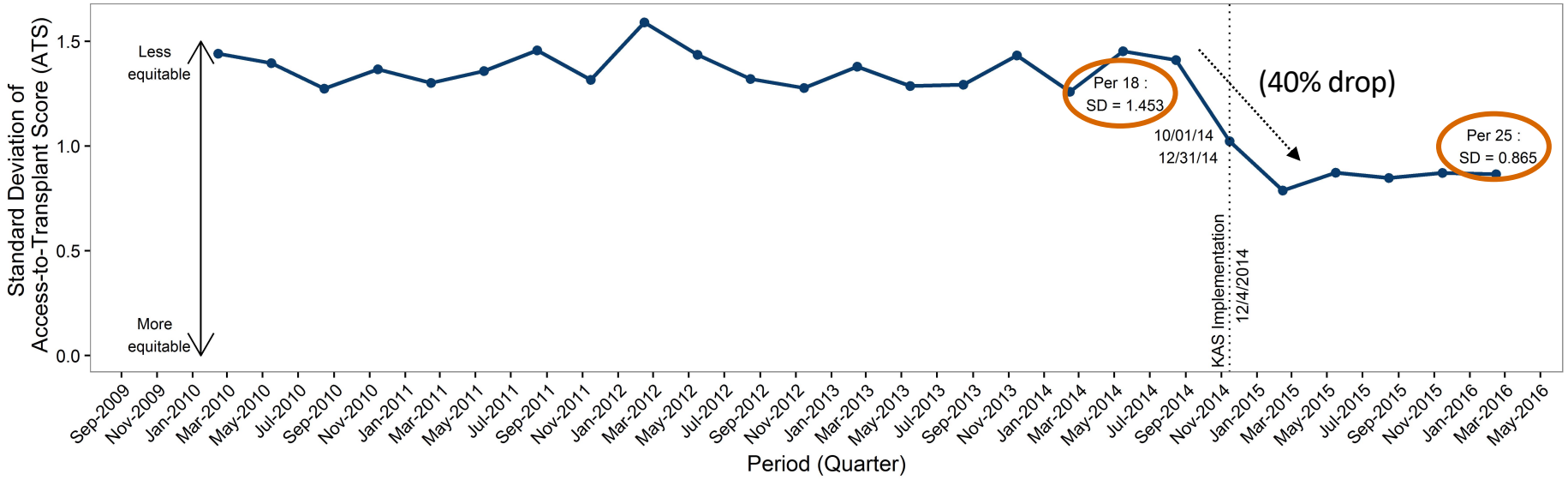
# Equity in Access

## Most Important Study Finding: KAS Increased Equity

Figure 3: Tracking Variability in Access-to-Transplant Score (ATS)
Among Waitlisted Kidney Candidates by Quarter (January 2010 - March 2016)




- Disparity in access (SD of ATS scores) decreased by 40% after KAS, suggesting that KAS led to improved equity in access.

*Stewart, Darren; Wilk, Amber; Cherikh, Wida; Harper, Ann; Urban, Read; Klassen, David; Edwards, Erick; "A New Methodology for Measuring and Monitoring Equity in Access to Deceased Donor Kidney Transplants", American Transplant Congress, Chicago, 2017.*

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# Ideas to Improve Transplant Access and Outcomes for Communities of Color

**Brendan Parent, JD**

**Feb 22 2022**

# Disclosure

Salary support from a gift from United Therapeutics

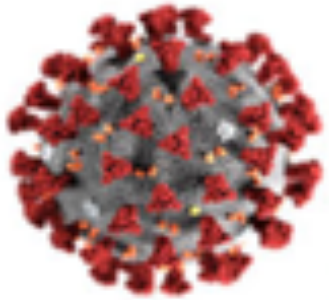
Applebaum grant studying ethics of xenotransplant

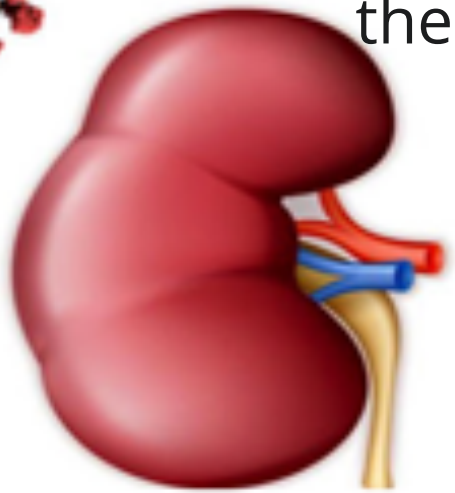
NFRF (Canada) grant, study of organ preservation and improvement/ organ bioengineering

NIH NHLBI grant, study of authorization for uncontrolled lung recovery

# COVID impact on transplant availability for minoritized populations

"Black patients are less likely to have access to transplantation, less likely to make it through the clinical evaluation process, and are likely to wait longer once listed"





"Black Americans represent a disproportionate share of those infected by [COVID-19], and those who succumb to the disease"

Purnell, Tanjala S., et al. "Dismantling structural racism as a root cause of racial disparities in COVID-19 and transplantation." *American Journal of Transplantation* 21.7 (2021): 2327-2332.

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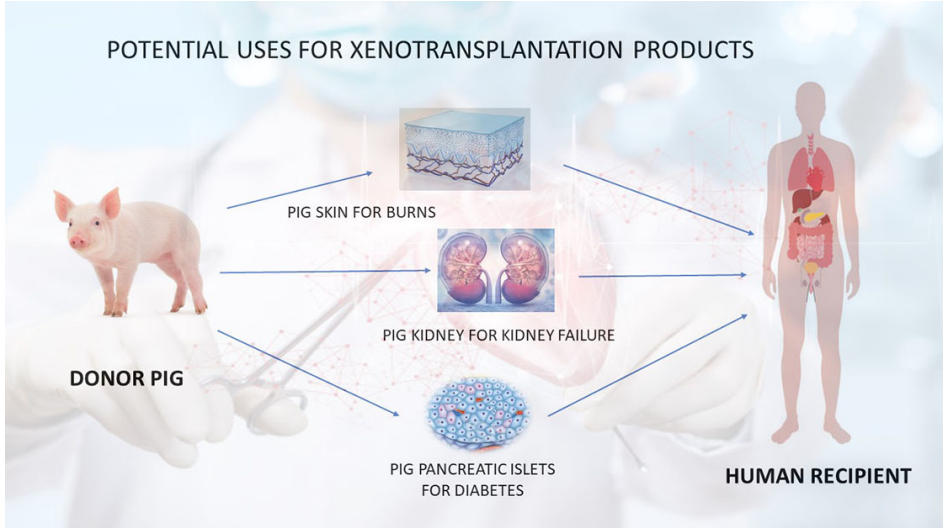
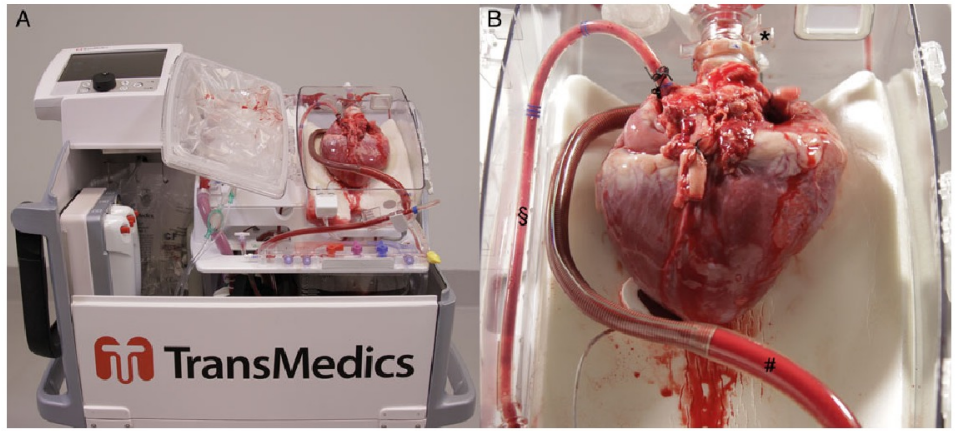
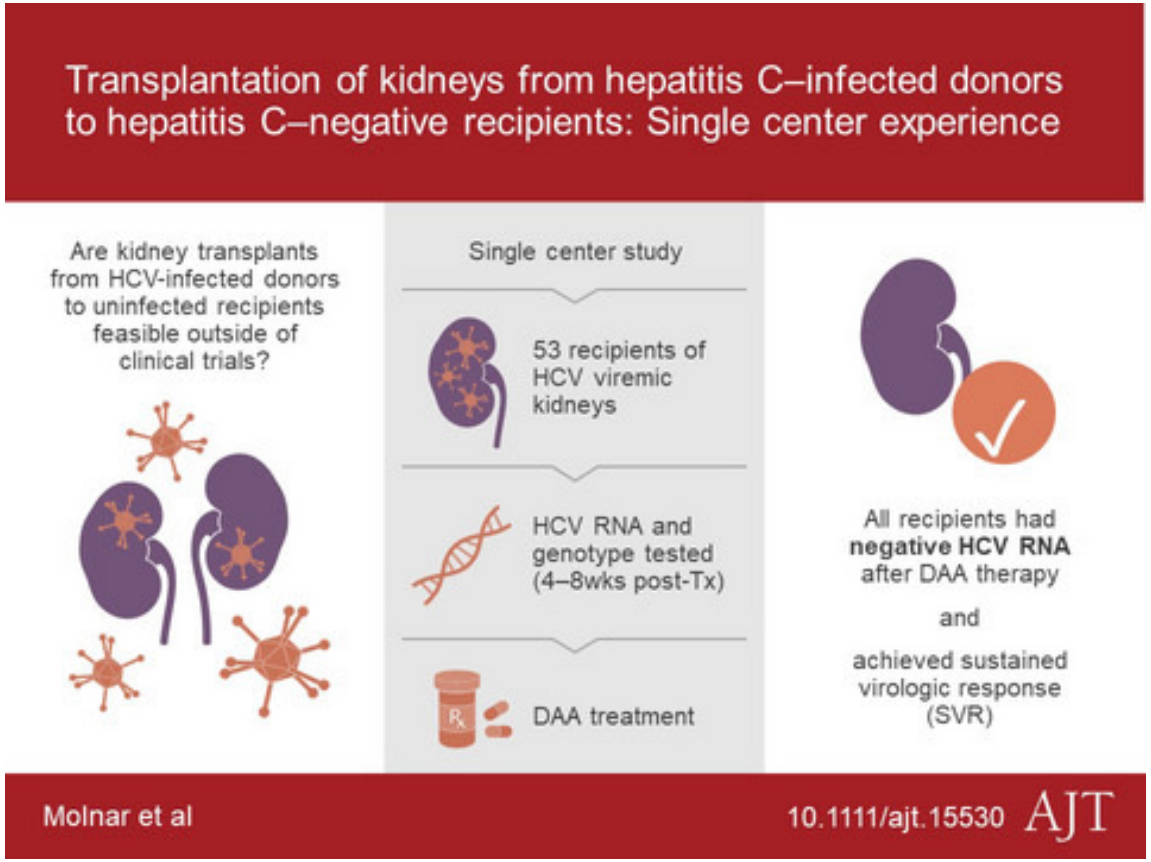
# Expand Organ Availability




The transport unit of the Organ Care System (Transmedics) with *ex vivo* perfusion of a porcine heart. The ascending aorta is connected to ar



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# Change OPTN MPSC Outcome Measures

- CMS changed in 2019: No more outcome reporting!
- BUT OPTN/MPSC has not caught up: Membership based on Graft/Patient Survival
  - **Potentially change requirement to be based on *patient-specific* comparison of survival and/or quality of life compared to projected *patient-specific* survival and/or quality of life without Tx**

OPTN | ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK

CMS CENTERS FOR MEDICARE & MEDICAID SERVICES

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# Improve referrals for Tx at Dialysis Centers

70% ESRD patients are on dialysis

Black dialysis patients less likely than white to report receiving info about Tx

| | Black/African American | | White | |
|---|---|---|---|---|
| | 2006 | 2015 | 2006 | 2015 |
| % patients receiving a kidney transplant within 3 y of ESRD | 9.1% | 7%** | 21% | 16.2** |

Laster M, Shen JI, Norris KC. Kidney Disease Among African Americans: A Population Perspective. *Am J Kidney Dis*. 2018;72(5 Suppl 1):S3-S7. doi:10.1053/j.ajkd.2018.06.021

CMS requires Tx referral w/in 45 days: Not enough!

Get independent entities to do Tx education in Dialysis Centers

# Reduce Financial Barriers to Tx

- Help the uninsured or underinsured to get insurance
- Those who cannot get insurance: Increase cost of all Tx to subsidize those without insurance/ Create Fund Pool
- Limit institutional cost burden: Generic immunosuppression meds; tailor follow-up care
- Universal Healthcare(!)(?)

# Evaluation for Mental Illness, Intellectual and Developmental Disability Further Complicate Eligibility

- Black (versus white) patients are more likely to be reported as unsuitable for transplantation because they are “psychologically unfit”
  - Burden of MI/ID/DD no greater for Black than white patients
  - **Solution? Root out biases, improve implicit bias training**

- MI/ID/DD contraindication mirrors lack of social support contraindication: Fear of bad outcomes due to poor compliance
  - **Solution? Help improve likelihood of compliance**

# Increase Social Worker and Home Aide Capacity

- Increase number of social workers/hire part time social workers
  - More dedicated in-hospital follow up
  - Regular house-calls for set period
  - Regular video-call follow up thereafter
- Tx center hire team of Home Aides for most vulnerable/isolated patients



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# Volunteer Nonprofit

- Get public involved
  - Certification to drive/accompany patients to appointments
  - House calls just to check in or deliver medications
  - Educate patients in dialysis centers

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# Technological Monitoring

- "Smart Tech"
  - Connected pill box
  - Ease-of-Use Self-Imaging

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# Transplant is a Bandaid – Let's prevent organ failure

## Social Determinants of Health

| Economic Stability | Neighborhood and Physical Environment | Education | Food | Community and Social Context | Health Care System |
|---|---|---|---|---|---|
| Employment | Housing | Literacy | Hunger | Social integration | Health coverage |
| Income | Transportation | Language | Access to healthy options | Support systems | Provider availability |
| Expenses | Safety | Early childhood education | | Community engagement | Provider linguistic and cultural competency |
| Debt | Parks | Vocational training | | Discrimination | Quality of care |
| Medical bills | Playgrounds | Higher education | | | |
| Support | Walkability | | | | |

**Health Outcomes**
Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations

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# Thank You

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# Pediatric Transplant and Disparities

Erin Paquette, MD, JD, Mbe

22 Feb 2022

BEST CHILDREN'S HOSPITALS U.S.News & WORLD REPORT HONOR ROLL 2017-18

THE LEAPFROG GROUP TOP CHILDREN'S HOSPITAL 2016

MAGNET RECOGNIZED AMERICAN NURSES CREDENTIALING CENTER

# Disclosures

- I am on the organ transplant committee for my primary institution.
- I am a liaison to Gift of Hope, our local organ procurement organization.
- I chair the Ethics Advisory Board, which hears cases with ethical concerns for transplantation.
- No conflicts of interest.

# Overall Goal Should Be to Promote Equity

- National Organ Transplant Act (1984)
  - "assure equitable access by patients to organ transplantation and assure the equitable allocation of donated organs among transplant centers and patients medically qualified for an organ transplant"
  - "identification of barriers to donation of organs to patients (with a special emphasis on pediatric patients)."

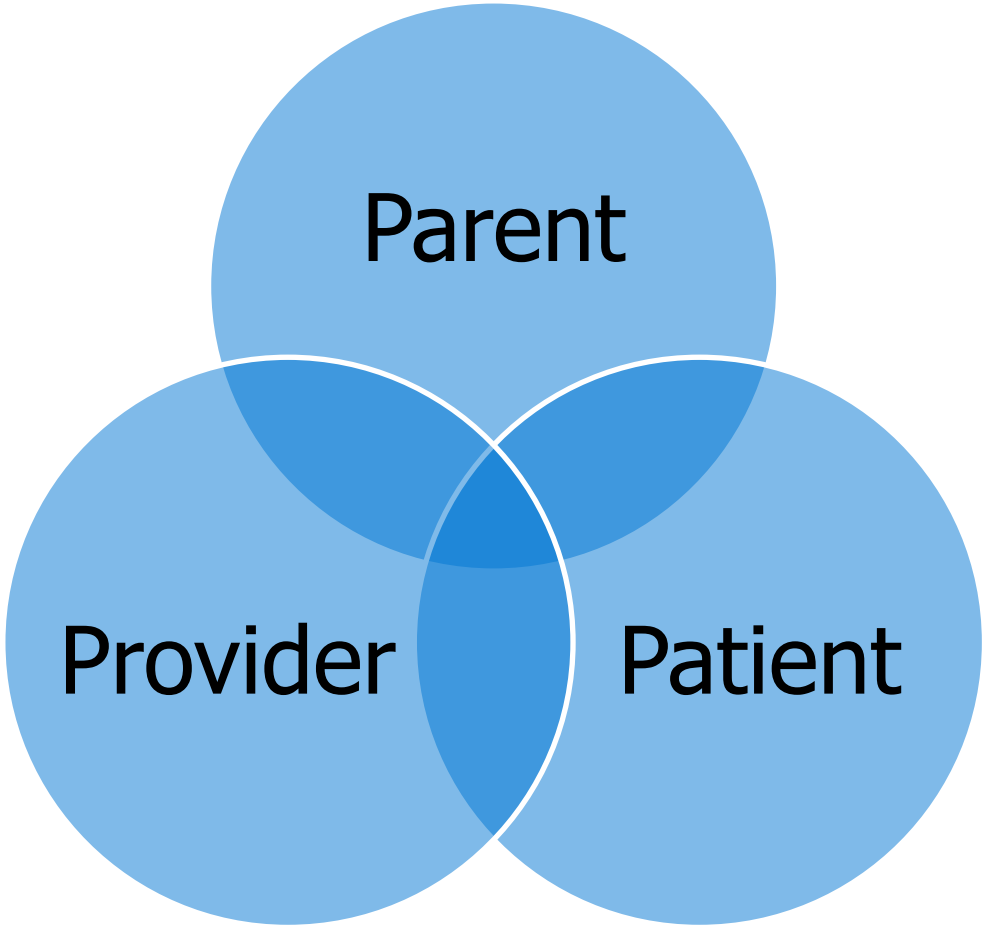
- Moral theories of allocation
  - Maximizing utility (efficiency)
  - Just distribution (equity)



Hsu, Perito, Mazariegos. Clinical Liver Disease 2021; 17(4): 312-316

# Transplantation in the Pediatric Population






- Several ethical arguments for prioritization of children for organ donation, which arguably lessens disparities in this population
  - Prudential lifespan account
    - Benefit over a lifetime
  - Maximin principle
    - Maximize worst off; children with early organ failure are worse off because occurs at earlier age
- Underlies prioritization of children with ESRD for kidney transplant; argued for in liver transplant
- Still, concerns regarding disparities in this population

# Disparities Exist Along the Continuum

Disparities by race, ethnicity, and socioeconomic status have been shown for patients with kidney, liver, lung failure in need of transplant

Kucirka LM, Grams ME, Balhara KS, Jaar BG, Segev DL. Am J Transplant 2012;12:351-7.
Monson RS, Kemerley P, Walczak D, Benedetti E, Oberholzer J, Danielson KK. Transplantation 2015;99:236-42.
Kucirka LM, Purnell TS, Segev DL. JAMA 2015;314:565-7.
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Mathur AK, Ashby VB, Fuller DS, Zhang M, Merion RM, Leicthman A, et al. Transplantation 2014;98:94-9.
Jesse MT, Abouljoud M, Goldstein ED, Rebhan N, Ho C-X, Macaulay T, et al. Clin Transplant 2019;33:e13714
Quon BS, Psoter K, Mayer-Hamblett N, Aitken ML, Li CI, Goss CH. Am J Respir Crit Care Med 2012;186:1008-13.

# Psychosocial Evaluation in Pediatric Patients (Case Example)

- Patient Knowledge and Motivation for Transplant
  - Lower health literacy in populations at risk for health disparities
- Mental health and substance abuse/use history
  - Parent and patient may be considered
  - Higher prevalence in populations at risk for health disparities
- Presence or absence of family/social support
  - Children in non-intimate families may be disadvantaged
- Availability of financial resources
  - Lower in individuals at risk for health disparities / lower SES
- Past history of treatment adherence
  - Compliance may be lower in populations at risk for health disparities
- Quality of the family's relationship with the transplant team
  - May be impacted by implicit or explicit biases on the part of the transplant team



Annunziato RA, Fisher MK, Jerson B, Bochkanova A, Shaw RJ. Psychosocial assessment prior to pediatric transplantation: A review and summary of key considerations. Pediatr Transplantation 2010: 14: 565–574

# Intellectual Disability

- Justifications for excluding those with ID from transplantation
  - Concerns regarding post-transplant regimen compliance (stewardship/allocation)
  - Expected lower quality of life than those with normal cognitive ability (benefit/utility)
  - Shorter life expectancy and comorbidities (benefit/utility)
- Use of minimum benefit threshold (life years) – 50% probability of survival at 5 years
- Existing data suggest similar short- and long- term survival for children with ID compared to other children
- Children with ID should meet minimum benefit threshold
- Does not account for QALYs. Disagreement about those in PVS and MCS.
- Existing ethical analysis supports *referral* and *individualized assessment* during evaluation as well as tracking of transplantation outcomes.

Ross LF. J Pediatr. 2021 Aug;235:6-9
Statter MB, Noritz G, the American Academy of Pediatrics Committee on Bioethics, Council on Children with Disabilities. Pediatrics 2020;145:e20200625
Wightman A, Bradford MC, Hsu E, Bartlett HL, Smith JM. Prevalence and long-term outcomes of solid organ transplantation in children with intellectual disability. 2021. J Pediatr. https://doi.org/10.1016/j.jpeds.2021.03.056

# Substance Use and Transplantation

- Lack of universal policies on evaluating for and incorporating substance use into transplant evaluation
- Mixed data on whether pre-transplant substance use predicts post-transplant adherence and outcomes
- Historical bias in who gets screened for substance use → may lead to discriminatory application of findings
- Need for development of policies with consideration for holistic substance use services rather than exclusion from referral, evaluation, transplantation

Monnin K, Lofton AM, Naclerio C, et al. Pediatr Transplant. 2021;25(4):e13984.
Lieber SR, Helcer J, Leven E, et al. Exp Clin Transplant. 2018;16(5):533-540.
Becker JH, Shemesh E, Shenoy A, et al. Prog Transplant. 2021;31(1):4- 12.
Arriola KJ. J Health Care Poor Underserved. 2017;28(1):30- 45.
Campagna BR, Annunziato RA. Pediatr Transplant. 2021 Aug;25(5):e14050

# Approaches to Concerns

- Exclusion
- Placement in medical foster care
- Listing for transplant

# Impact of COVID

- Heightened attention to scarcity of resources
  - Increased sense of stewardship
  - May perpetuate biases/discrimination
- Delays in seeking care
  - Delayed referral and evaluation

# A way forward

- Heightened awareness/open dialogue
- Rigorous analysis of available data on referrals/evaluations/transplantation within and across centers
- Intentional equity lens

Questions?

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# A Special Thanks to Our Panelists

**Winfred Williams**

MD

Associate Chief of Nephrology; Founding Director, Center for Diversity & Inclusion

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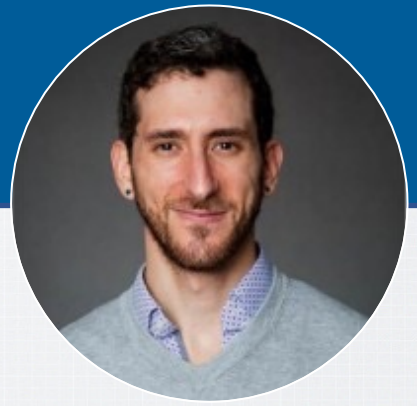

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Q&A
QUESTIONS & ANSWERS