



## Methods to improve the measurement of kidney transplant referral rates with incomplete transplant center data

Journal:	<i>Clinical Transplantation</i>
Manuscript ID	CLTX-25-LTE-0163
Wiley - Manuscript type:	Letter to the Editor
Date Submitted by the Author:	20-Feb-2025
Complete List of Authors:	Ross-Driscoll, Katie; Indiana University Department of Surgery; Regenstrief Institute Inc; Indiana University Indianapolis Richard M Fairbanks School of Public Health Di, Mengyu; Regenstrief Institute Inc Harding, Jessica; Emory University Department of Surgery Buford, Jade; Regenstrief Institute Inc Britt-Spells, Angelitta; Indiana University Indianapolis Richard M Fairbanks School of Public Health Laster, Marciana; Indiana University School of Medicine Wilk, Adam S.; Indiana University Department of Surgery; Regenstrief Institute Inc Pastan, Stephen; Emory University Department of Medicine E, Rachel Patzer; Indiana University Department of Surgery; Regenstrief Institute Inc
Transplant Peer Review Network - Second Choice:	No referral
Transplant Peer Review Network - First Choice:	No referral
Discipline:	kidney transplantation/nephrology, social sciences
Keywords:	kidney transplantation: living donor, patient referral, statistics
Abstract:	n/a

Methods to improve the measurement of kidney transplant referral rates with incomplete  
transplant center data

**Running title:** Measuring kidney referral rates

**Key words:** kidney transplant; referral; statistical methods; adjustment

Katie Ross-Driscoll, PhD, MPH, Mengyu Di, MPH, Jessica Harding, PhD, Jade Buford, MPH,  
Angelitta Britt-Spells, PhD, MPH, MS, Marciana Laster, MD, MSCR, Adam S. Wilk, PhD,  
Stephen Pastan, MD, Rachel E. Patzer, PhD, MPH

**ORCID:**

Ross-Driscoll: 0000-0002-1176-3172

X: @kross\_epi

Di: 0000-0001-9854-4791

Harding: 0000-0002-6664-8630

Buford: 0000-0002-8819-6188

Britt-Spells: 0009-0006-1369-1666

Laster: 0000-0001-6817-2448

Wilk: 0000-0003-4831-0692

X: @adamswilk

Pastan: 0000-0003-2638-6354

Patzer: 0000-0003-2573-9963

X: @RachelPatzerPhD

**Affiliations:**

KRD:

1. Division of Transplant Surgery, Department of Surgery, Indiana University School of Medicine, Indianapolis, IN
2. Center for Health Services Research, Regenstrief Institute, Indianapolis, IN
3. Department of Epidemiology, Richard M. Fairbanks School of Public Health, Indiana University Indianapolis, Indianapolis, IN

MD:

1. Center for Health Services Research, Regenstrief Institute, Indianapolis, IN

JH:

1. Department of Surgery, Emory University School of Medicine, Atlanta, GA

BJ:

1. Center for Health Services Research, Regenstrief Institute, Indianapolis, IN

ABS:

1. Department of Epidemiology, Richard M. Fairbanks School of Public Health, Indiana University Indianapolis, Indianapolis, IN

ML:

1. Department of Pediatric Nephrology, Indiana University School of Medicine, Indianapolis, IN

AW:

1. Division of Transplant Surgery, Department of Surgery, Indiana University School of Medicine, Indianapolis, IN
2. Center for Health Services Research, Regenstrief Institute, Indianapolis, IN

SP:

1. Division of Nephrology, Department of Medicine, Emory University School of Medicine, Atlanta, GA

RP:

1. Division of Transplant Surgery, Department of Surgery, Indiana University School of Medicine, Indianapolis, IN
2. Center for Health Services Research, Regenstrief Institute, Indianapolis, IN

**Corresponding Author:**

Rachel E. Patzer, PhD, MPH

1101 W 10<sup>th</sup> Street

Indianapolis, IN 46202

Phone: 608-438-0323

Email: [rapatzer@regenstrief.org](mailto:rapatzer@regenstrief.org)

Word count: 747 (limit: 750)

Tables and figures: 2 (limit: 2)

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## Introduction

Prior studies have identified differences in kidney transplant rates across the nation, potentially due to differences in referral patterns. The Early Steps to Transplant Access Registry (E-STAR)<sup>1</sup> – currently the only population-based source of kidney transplant referral data in the nation – is voluntary, resulting in potentially inaccurate referral measurement in regions without complete transplant center participation. Adjusting the denominator of referral rates (i.e., person-time from incident dialysis patients) to reflect transplant center participation may improve accuracy. These methods would be particularly relevant for upcoming national referral data collection efforts, which may not have 100% initial participation.<sup>2</sup> We used data from a network with 100% participation in E-STAR (Network 6) to simulate the impact of incomplete center participation on referral measurement and test methods of denominator adjustment to improve accuracy.

## Methods

### *Data Source*

We included E-STAR data from the 9 adult kidney transplant centers active in ESRD Network 6 (GA, NC, SC) from 1/1/2015 to 12/31/2019. Data on adult patients living in Network 6 who initiated dialysis in the same period were obtained from the United States Renal Data System (USRDS) (n = 49,613).<sup>3</sup> We assigned patients to a transplant center catchment area based on their home ZIP; catchment areas are described elsewhere.<sup>4</sup> “Market share” for each center was calculated as center transplant volume divided by the total number of transplants performed in the network in the study period.

### *Methods*

Similar to other studies, we defined “referral” as referral to a transplant center within 1 year of dialysis start. We calculated a “gold standard” referral rate (i.e. number of referrals divided by the total person-time on dialysis among incident patients in the network) using data from all centers. Next, we identified all possible combinations of < 9 centers (i.e. 36 possible combinations of 7 centers), totaling 510 combinations. We calculated four denominators per combination (Table 1): unadjusted, market share-adjusted, catchment area-adjusted, and adjusted for both market share and catchment area. From these denominators we calculated four rates for each combination, along with the median and IQR for all possible combinations, stratified by the number of included centers (i.e. a median and IQR for each rate for 7 participating centers). This study was approved by the institutional review boards at Emory (IRB00113572) and Indiana (IRB18998) University.

## Results

Referral within 1 year of dialysis initiation in Network 6 was 36%. Including data from one transplant center (11% participation) underestimated the referral rate 10-fold (median: 3.4%, IQR: 1.6%, 7.7%) (Figure 1). Adjusting for catchment area reduced the degree of underestimation (median: 20.9%, IQR: 14.9%, 29.6%). The median market share-adjusted rate overestimated the gold standard by 5 percentage points (median: 41.0%, IQR: 33.2%, 49.4%); results for one center were similar when adjusting for both market share and catchment area.

The extent of underestimation for unadjusted and catchment-area adjusted rates declined with increasing center inclusion; overestimation for market share-adjusted rates remained similar

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3 regardless of the number of included centers. Catchment-area adjustment began outperforming  
4 market share adjustment at 77% center participation (-2.3 percentage-point difference from gold  
5 standard vs. 4.2 percentage-point difference).  
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## 7 **Discussion**

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9 In this analysis, we found that incomplete center participation resulted in underestimation of the  
10 overall network referral rate; estimation improved with increasing center participation and after  
11 adjustment for catchment area. With low transplant center participation, market share-  
12 adjustment produces the referral rate most similar to the gold standard; catchment area-  
13 adjustment produces the referral rate most similar to the gold standard; catchment area-  
14 adjustment may be more appropriate with high (> 75%) center participation.  
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18 The new Organ Procurement and Transplant Network (OPTN) directive includes national  
19 collection of referral data.<sup>2</sup> The initial phase of data collection may begin with a voluntary rollout  
20 and experience additional challenges, including delays and data entry errors. Our results  
21 demonstrate how referral rates can still be calculated without complete data. This is particularly  
22 important in the context of the Increasing Organ Transplant Access (IOTA) payment model, a  
23 recently implemented policy initiative.<sup>5</sup> Applying our methods could help ensure that even  
24 incomplete referral data can be rapidly used to support these initiatives.  
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30 Our findings are subject to limitations. The “gold standard” referral rate may itself be an  
31 underestimate as it does not include patients referred outside of Network 6. “Volume” as a  
32 market share measure is a lagging indicator that is downstream of referral and may miss  
33 secular trends in referral. Despite these limitations, our results indicate that referral rates can be  
34 estimated even without complete transplant center data using denominator adjustment. These  
35 results may help inform HRSA’s planned national referral data collection rollout and support  
36 measuring referral in other contexts, such as dialysis facilities.  
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**Author contributions:** research idea and study design: KRD, JB, RP; data acquisition: JH, JB, SP, REP; statistical analysis: MD; data interpretation: KRD, JH, JB, ABS, ML, JH, AW, SP, REP; supervision or mentorship: REP. Each author contributed important intellectual content during manuscript drafting or revision and agrees to be personally accountable for the individual's own contributions and to ensure that questions pertaining to the accuracy or integrity of any portion of the work, even one in which the author was not directly involved, are appropriately investigated and resolved, including with documentation in the literature if appropriate.

**Acknowledgments:** KRD is funded by K01MD018455. E-STAR is funded by R01DK122701 and U01MD0100611. The data reported here have been supplied by the United States Renal Data System (USRDS). The interpretation and reporting of these data are the responsibility of the author(s) and in no way should be seen as an official policy or interpretation of the U.S. government.

**Conflict of Interest:** The authors have no conflicts of interest to disclose.

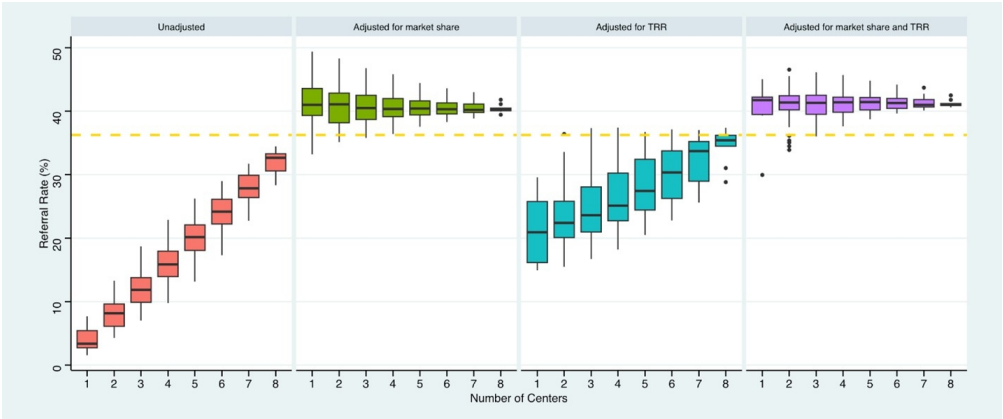
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## Figure legend

**Figure 1.** Median and interquartile range (IQR) of calculated within facility kidney transplant referral rates for all possible combinations of 1-8 transplant centers in GA, NC, and SC.



165x68mm (220 x 220 DPI)



**Table 1.** Denominator adjustments.

Adjustment	Description
Unadjusted	All incident adult ESKD patients in Network 6
Adjusted for market share	All incident adult ESKD patients in Network 6, multiplied by the proportion of transplants performed in Network 6 by included centers
Adjusted for catchment area	All incident adult ESKD patients living in catchment areas served by included centers
Adjusted for catchment area and market share	All incident adult ESKD patients living in catchment areas served by included centers, multiplied by the proportion of transplants performed in Network 6 by included centers

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