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# Social determinants of health data in solid organ transplantation: National data sources and future directions

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# Abstract

Health equity research in transplantation has largely relied on national data sources, yet the availability of social determinants of health (SDOH) data varies widely among these sources. We sought to characterize the extent to which national data sources contain SDOH data applicable to end-stage organ disease (ESOD) and transplant patients. We reviewed 10 active national data sources based in the United States. For each data source, we examined patient inclusion criteria and explored strengths and limitations regarding SDOH data, using the National Institutes of Health PhenX toolkit of SDOH as a data collection instrument. Of the 28 SDOH variables reviewed, eight-core demographic variables were included in 80% of the data sources, and seven variables that described elements of social status ranged between 30 and 60% inclusion. Variables regarding identity, healthcare access, and social need were poorly represented ( 20%) across the data sources, and five of these variables were included in none of the data sources. The results of our review highlight the need for improved SDOH data collection systems in ESOD and transplant patients via: enhanced inter-registry collaboration, incorporation of standardized SDOH variables into existing data sources, and transplant center and consortium-based investigation and innovation.

#### DISCLOSURE

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Study concept and design: LMM, NWC, ADK. Review of data source information and data extraction: NWC, MMM. Drafting and critical revision of the manuscript: NWC, MMM, JBH, HZ, MPS, NAB, LMM. Final approval and agreement to be accountable for all aspects of the work: NWC, MMM, JBH, HZ, MPS, NAB, SB, ADK, LMM.

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Additional supporting information can be found online in the Supporting Information section at the end of this article.

#### Keywords

clinical research/practice; disparities; epidemiology; health services and outcomes research; Scientific Registry for Transplant Recipients (SRTR); solid organ transplantation; social sciences; United Network for Organ Sharing (UNOS)

# 1 | INTRODUCTION

Organ transplantation is a complex multidisciplinary field that delivers quaternary therapies to high-acuity patients in an environment where demand exceeds supply. National data registries are important tools for researchers looking to advance the field of organ transplantation. Registry-based studies are relatively quick and inexpensive to conduct, and the large sample size and multicenter representation increase study power and population heterogeneity. The results of registry-based research can also be applied broadly, as population-based cohorts are subject to real-world conditions over a longitudinal period.<sup>1,2</sup>

It is well-documented that historically marginalized groups, including women, racial and ethnic minority groups, and patients with low educational attainment or income, experience inequities along the entire transplant care continuum.<sup>3–7</sup> Research to identify root causes of these inequities and, in turn, develop and test interventions to reduce or eliminate them, has traditionally relied on national data registries. However, end-stage organ disease (ESOD) and transplant patients are frequently under-represented in public health databases due to population sampling or exclusion criteria, and social determinants of health (SDOH) availability varies across transplant-specific registries.

Prior work has demonstrated patient homogeneity in national datasets and biorepositories due to rigid eligibility criteria, and resultant low analytical and clinical utility for underrepresented communities.<sup>8</sup> In order to identify strategies to address the current limitations in SDOH data, we sought to characterize the extent to which national data sources contain metrics of SDOH, focusing on their applicability to ESOD and transplant populations.

# 2 | METHODS

We selected active data sources based in the United States consisting of transplant-specific registries, national public health datasets, and commercial databases based on a published systematic review of transplant equity literature that adhered to PRISMA reporting guidelines and searched the MEDLINE, Embase, CINAHL Complete, and Web of Science Core Collection databases.<sup>9</sup> We cross-referenced our initial selections with Google Dataset searches for "transplantation"<sup>10</sup> and "social determinants of health."<sup>11</sup>

For each data source, we examined the completeness of SDOH data and the inclusion of ESOD and transplant populations. Each data source's information guide was reviewed for collection methods and cohort definitions. Data dictionaries and data collection forms were assessed for the percentage of inclusion of 28 SDOH variables from the National Institutes of Health (NIH) PhenX Toolkit, a set of standardized measurement protocols used in health equity research.<sup>12,13</sup> Patient-level data elements and most current collection forms

were reviewed. A set of inclusion criteria was used to evaluate certain SDOH variables (Supplemental Digital Content [SDC] 1). Each source's point of contact was contacted to verify initial findings.

# 3 | RESULTS

We reviewed 10 data sources based in the United States and summarized data collection forms (Table 1) and SDOH inclusion (Table 2). The most commonly collected variables were: age, race and ethnicity, health insurance coverage, employment status, sex assigned at birth, and zip code-derived variables (air quality index, concentrated poverty, and community educational attainment); each was collected by greater than 80% of data sources. Variables describing elements of social status (e.g., immigration status, marital status, occupational prestige) ranged between 30 and 60% inclusion. Variables regarding personal identity, healthcare access, and social need were poorly represented (20%) across the sources with five variables (access to health services, discrimination, disparate health care quality, gender identity, and health numeracy) collected in none of the sources. Supplemental details of each source's collection methodology, protocols, and inclusion and exclusion criteria are included in a technical appendix S1 (SDC 2).

#### 3.1 | Transplant-Specific Registries

**3.1.1 United Network of Organ Sharing (UNOS)**—Established by the US Congress in 1984 to improve organ allocation, the Organ Procurement and Transplantation Network (OPTN) is operated by the non-profit organization UNOS under contract with the US Department of Health and Human Services (HHS).<sup>1,14</sup> An internet-based system, UNet, is used to store all OPTN data related to the national waitlist, organ matching, and transplant procedures.<sup>15</sup> Data are collected from transplant hospitals, histocompatibility laboratories, and organ procurement organizations (OPOs) and include all organ donors, transplant recipients, and transplant events since 1987; 13 SDOH variables are collected in UNOS.

**3.1.2** | Scientific Registry of Transplant Recipients (SRTR)—SRTR is a national registry overseen by HHS. Founded in 1987, SRTR primarily obtains data about waitlist candidates and transplant recipients from OPTN and incorporates information from state agencies, insurance claims, and the Social Security Administration.<sup>16</sup> Using Centers for Medicare and Medicaid Services (CMS) data, SRTR exhibits improved ascertainment of kidney graft loss compared to UNOS.<sup>1</sup> All living and deceased donors, transplant candidates, and organ recipients are included; 12 SDOH variables are collected in SRTR.

**3.1.3** | United States Renal Data System (USRDS)—USRDS is a national data system that collects, analyzes, and distributes information about chronic kidney disease (CKD) and end-stage renal disease (ESRD) patients. Established in 1988 by the National Institutes of Diabetes and Digestive and Kidney Diseases, USRDS contains demographic and clinical data on all ESRD patients requiring dialysis or kidney transplant since 1995. USRDS primarily uses CMS, OPTN, and Centers for Disease Control and Prevention (CDC) data to study transplant access, complications, and survival.<sup>17</sup> USRDS includes patients

irrespective of transplant status, enabling broader analysis of ESRD patients compared to UNOS<sup>1</sup>; 12 SDOH variables are collected in USRDS.

#### 3.2 | Other national data sources

**3.2.1 National Inpatient Sample (NIS)**—NIS is sponsored by HHS and is the largest publicly available, all-payer inpatient database in the US, estimating over 35 million hospitalizations. Developed in 1988, NIS contains private and federal data from the State Inpatient Databases and is used for research on healthcare cost, quality, outcomes, and policy.<sup>18</sup> NIS contains information unavailable in OPTN (e.g., charges, comorbidities); however, OPTN data cannot be linked because NIS identifiers are confidential. Although data are not broadly collected regarding ESOD and transplant patients, NIS includes ESOD patients regardless of transplant status in its sampling of hospitalizations<sup>1,18</sup>; 4 SDOH variables are collected in NIS.

**3.2.2** | American Community Survey (ACS)—ACS is an annual survey that provides demographic information about the US population through random surveying of 3.5 million households nationwide. Created by the US Census Bureau in 2005 to replace the decennial long-form census, ACS is a policy tool that aids in the distribution of federal and state funds and describes changes within communities each year.<sup>19</sup> As ACS uses random sampling, a sample of ESOD and transplant patients is included; however, data are not intentionally collected regarding these populations. Data collected include social, economic, housing, and demographic characteristics in populations of 65 000 or more; 20 SDOH variables are collected in ACS.

**3.2.3** | Centers for Medicare and Medicaid Services (CMS)—CMS is an HHS federal agency that stores data regarding patients utilizing CMS services in the Data Elements Library, a publicly accessible, centralized database. Since 2018, this database has been used by providers and researchers to facilitate interoperability and information exchange between electronic health records (EHRs).<sup>20</sup> CMS data originate from patient assessment instruments completed by providers for consideration of select services (e.g., hospice care, skilled nursing facilities, home health services). CMS includes ESOD and transplant patients who use CMS services, but does not purposefully collect data regarding these populations; 12 SDOH variables are collected in CMS.

#### 3.2.4 | National Health and Nutrition Examination Survey (NHANES)—

NHANES is a nationwide survey to assess the overall nutrition and health of adults and children in the United States. Created in 1960 by the CDC, NHANES is administered annually to a sample of 5000 randomly selected participants representing the non-institutionalized civilian population. As NHANES uses random sampling, a sample of ESOD and transplant patients is included; however, data are not intentionally collected regarding these populations. Data are gathered through in-person interviews, physical examinations, and laboratory specimen collections. These data underlie national standards for measurements (e.g., height, weight, blood pressure) and are used for epidemiological studies, health promotion, and disease prevention<sup>21</sup>; 22 SDOH variables are collected in NHANES.

**3.2.5** | **Truven health analytics MarketScan research databases**—The MarketScan Research Databases contain proprietary, de-identified administrative claims data for publicly and privately insured individuals in the United States. Developed in 2021 by Truven Health Analytics, MarketScan provides analytic tools and services to government agencies, hospitals, and private healthcare industries.<sup>22</sup> Data sources vary based on the population included in a specific database (e.g., oncology practices, skilled nursing facilities). MarketScan includes ESOD and transplant patients across its various claims databases, but does not broadly collect data regarding these populations; 4 SDOH variables are collected in MarketScan.

#### 3.2.6 | Vizient clinical data base (formerly University HealthSystem

**Consortium)**—Vizient is a private US healthcare performance improvement company that established the Vizient Clinical Data Base in 2016 during a merger with University HealthSystem Consortium. Vizient provides analysis of patient outcomes (e.g., mortality, length of stay, readmission rates) to participating hospitals to facilitate quality improvement goals and performance assessments.<sup>23</sup> Data are uploaded at the patient level from over 200 academic and community hospitals. Vizient includes ESOD and transplant patients within its outcomes database, but does not broadly collect data regarding these populations; 7 SDOH variables are collected in Vizient.

**3.2.7** | National surgical quality improvement program (NSQIP)—Established in the early 1990s, the Veterans Affairs Surgical Quality Improvement Program (VASQIP) identifies postoperative complications and outcomes at Veterans Affairs facilities through manual data extraction by nurse coordinators.<sup>24</sup> VASQIP inspired the American College of Surgeons to create NSQIP in 2004 to improve surgical quality and outcomes across specialties using inpatient and outpatient surgical data.<sup>25</sup> The Transplant Quality Improvement Program (TransQIP) was established in 2017 with a sole focus on improving liver and kidney transplant outcomes using patient-level data variables from OPOs.<sup>26</sup> Unlike TransQIP, NSQIP, and VASQIP do not purposefully collect data regarding ESOD and transplant populations; 10 SDOH variables are collected across NSQIP databases.

## 4 | DISCUSSION

National data sources have long been used to describe disparities in transplantation, but causality between SDOH and clinical outcomes among ESOD and transplant patients has not been well-established, due in part to data limitations. We characterized SDOH availability in national data sources, using the NIH PhenX toolkit as a measurement tool for classification, to identify opportunities to accelerate health equity research in transplant.

Transplant-specific registries (UNOS, SRTR, USRDS) exhibited a moderate degree of SDOH inclusion (42.9–46.4%) with variation in the extent of SDOH data obtained for living donors, deceased donors, and transplant recipients. We did not find variation in the SDOH variables collected by organ type. The most comprehensive data sources were ACS (71.4%) and NHANES (78.6%). These population-based surveys represent the current gold standard for SDOH capture but were not intentionally designed to identify ESOD and transplant patients. The least comprehensive data sources were the Truven Health Analytics

MarketScan Research Databases (14.3%), NIS (14.3%), Vizient Clinical Data Base (25%), and NSQIP databases (35.7%). MarketScan and Vizient consolidate large amounts of patient data across health systems; however, they were designed for quality improvement, which has historically focused on health system-driven clinical interventions over SDOH. TransQIP offers the potential for reducing transplant inequities using multicenter data; however, its use in analyzing national SDOH data has not been described.<sup>26</sup>

Our review highlights the need for improved SDOH data collection systems in ESOD and transplant patients via: (1) enhanced inter-registry collaboration, (2) incorporation of standardized SDOH variables into existing data sources, and (3) transplant center and consortium-based investigation and innovation.

#### 4.1 | Enhanced inter-registry collaboration to maximize the use of existing data

There is currently no universal registry of SDOH data sources. Health equity research is limited by ethico-legal, technical, financial, and political difficulties in combining SDOH sources<sup>27</sup>; and the rapid proliferation of health system- and payor-based datasets adds complexity to an already uncoordinated data infrastructure. UNOS's ongoing project to link third-party data to OPTN models the type of collaboration that would reduce the burden on individual researchers while maximizing the use of our currently available data. The project's phases reflect tangible action items that other transplant-specific registries can model in creating SDOH research protocols: (1) data evaluation, to determine SDOH variables to be collected; (2) data acquisition, to establish external relationships for SDOH data supplementation and complex data linkage; and (3) data analysis, to perform SDOH quality review and develop research recommendations,<sup>28</sup> Additionally, federal cross-agency partnerships among the US Census Bureau, NIH, and CDC could combine siloed funding streams and link comprehensive SDOH datasets to critically augment registry data.<sup>29</sup> Linkage of a standardized set of SDOH variables is a prerequisite for a coordinated and systematic approach to equity through inter-registry collaboration, as demonstrated in the Standardized Outcomes in Nephrology initiative for CKD.<sup>30</sup> This is one purpose of the NIH PhenX toolkit, which has yet to gain traction in transplantation; it is also essential to bolstering SDOH representation in other data sources containing ESOD and transplant populations.

#### 4.2 | Incorporation of standardized SDOH variables into existing data sources

Well-established transplant registries have been instrumental in monitoring the quality of care over time and identifying areas of actionable intervention. Registries were designed, however, to improve clinical outcomes rather than investigate social context—reasonably accounting for the relative paucity of SDOH. Updating SRTR and USRDS collection forms with standardized and expanded SDOH variables can drastically support efforts like the aforementioned UNOS project. Research using expanded SDOH variables (e.g., health literacy, English proficiency, food insecurity) demonstrates that these infrequently assessed factors significantly mediate center-level kidney and liver transplant outcomes and may even perpetuate pre-existing racial disparities in transplantation, emphasizing the importance of their collection.<sup>31–34</sup> Incorporation of expanded SDOH variables into existing data sources is also a requisite step toward equitable policy design and implementation. For example, the

US Census Bureau issued the Household Pulse Survey in April 2020 to support COVID-19 recovery efforts through detailed SDOH data collection, including food insecurity, sexual orientation, and gender identity—among the most poorly collected variables in our review. Federal agencies subsequently tailored recovery planning to findings of higher rates of food insecurity, income loss, and depression in LGBTQ+ respondents.<sup>35</sup>

Expanding SDOH data collection requires salient practical considerations such as economic feasibility and efficient data collection. Seamless integration of SDOH collection into current workflows and staffing models is vital to minimizing the regulatory burden on transplant centers. Ambulatory clinics may be the most opportune setting for data collection, allowing for repeated collection across the transplant care continuum and multiple opportunities to bridge SDOH information gaps in the EHR.

Other considerations to minimize administrative burden include: electronic alternatives for patient self-reported data without staff documentation (e.g., tablets in clinic rooms, questionnaires administered via text, patient portals); EHR alerts for patients with missing or outdated SDOH data; text shortcut tools for SDOH-related documentation; and compensated, staff-driven workflow reviews to minimize duplicative and inefficient processes.<sup>36</sup> Center-specific data needs must also be balanced with nationally standardized metrics and validated tools to ensure rigor in methodology. Engaging broad stakeholder perspectives (clinicians, patients, administrators) is, therefore, a critical starting point for center-specific solution design.<sup>36,37</sup> Federal initiatives offering financial incentives for equity-focused metrics in pre-existing review structures, such as CMS Quality Assurance and Performance Improvement, can support health systems in fulfilling this work.<sup>37</sup> US Congress can further promote the importance of SDOH through the passage of legislative bills, such as the Improving Social Determinants of Health Act of 2021, that fund interagency collaboration and technology-based solutions to reduce health disparities.<sup>29</sup>

#### 4.3 | Transplant center and consortium-based investigation to accelerate innovation

Until the development of a unified system to collect and study SDOH, center-based approaches are uniquely positioned to combine clinical and operational expertise with community engagement. Health system data allow detailed characterization of centerspecific SDOH and patient challenges. Health systems can also develop and test interventions aimed against institutional, interpersonal, and systemic biases through quality and performance services. These local efforts can facilitate rapid iteration, system redesign, and early engagement with patient and community stakeholders. For true impact to be realized, SDOH collection must encompass ESOD and transplant populations consistently and thoroughly. USRDS, for example, has demonstrated profound influence on ESRD care; yet, similar focused data do not exist for end-stage liver disease patients. The specificity of single-organ registries must be continually applied to efforts, such as TransQIP, that pool center-specific data at a national level for increased research efficacy. Multicenter consortiums, such as the Southeastern Kidney Transplant Coalition,<sup>38</sup> draw upon local knowledge and experiences of high-performing health systems while supplying necessary heterogeneity in populations of interest, SDOH-specific barriers, and geographic mediators to truly accelerate innovation in transplant equity.

# 5 | CONCLUSION

National data sources are fragmented and insufficient in scope for research on health equity in transplantation. Transplant-specific registries collect only core SDOH variables; meanwhile, national data sources exhibit a great capacity for comprehensive SDOH collection but are limited in applicability to ESOD and transplant populations. The lack of expanded SDOH availability has relegated the field to a superficial—and occasionally inaccurate—understanding of how social barriers affect access to and success following transplant. If transplant-specific registries and SDOH datasets remain siloed in data collection, root causes of transplant inequities will remain obscured. Improving the representation of expanded SDOH in our current data framework is, therefore, a vital step to implementing changes that promote equitable evaluation, listing, and allocation of organs.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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# DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analyzed during the current study.

### Abbreviations:

ACS	American Community Survey
CDC	Centers for Disease Control and Prevention
CKD	chronic kidney disease
CMS	Centers for Medicare and Medicaid Services
EHR	electronic health record
ESOD	end-stage organ disease
ESRD	end-stage renal disease
HHS	United States Department of Health and Human Services
IBM	International Business Machines

NHANES	National Health and Nutrition Examination Survey
NIH	National Institutes of Health
NIS	National Inpatient Sample
NSQIP	National Surgical Quality Improvement Program
ОРО	organ procurement organization
OPTN	Organ Procurement and Transplantation Network
SDC	Supplemental Digital Content
SDOH	social determinants of health
SRTR	Scientific Registry of Transplant Recipients
TCR	transplant candidate registration (OPTN form)
TransQIP	Transplant Quality Improvement Program
TRF	transplant recipient follow-up (OPTN form)
TRR	transplant recipient registration (OPTN form)
UNOS	United Network of Organ Sharing
USRDS	United States Renal Data System
VASQIP	Veterans Affairs Surgical Quality Improvement Program

# REFERENCES

- Massie AB, Kucirka LM, Segev DL. Big data in organ transplantation: registries and administrative claims. Am J Transplant. 2014;14(8):1723–1730. doi:10.1111/ajt.12777 [PubMed: 25040084]
- Ng MSY, Charu V, Johnson DW, O'Shaughnessy MM, Mallett AJ. National and international kidney failure registries: characteristics, commonalities, and contrasts. 2021. doi:10.1016/ j.kint.2021.09.024
- Schold JD, Gregg JA, Harman JS, Hall AG, Patton PR, Meier-Kriesche HU. Barriers to evaluation and wait listing for kidney transplantation. Clin J Am Soc Nephrol. 2011;6(7):1760–1767. doi:10.2215/cjn.08620910 [PubMed: 21597030]
- 4. Patzer RE, Perryman JP, Schrager JD, et al. The role of race and poverty on steps to kidney transplantation in the southeastern United States. Am J Transplant. 2012;12(2):358–368. doi:10.1111/j.1600-6143.2011.03927.x [PubMed: 22233181]
- Monson RS, Kemerley P, Walczak D, Benedetti E, Oberholzer J, Danielson KK. Disparities in completion rates of the medical prerenal transplant evaluation by race or ethnicity and gender. Transplantation. 2015;99(1):236–242. doi:10.1097/tp.000000000000271 [PubMed: 25531896]
- Freeman MA, Pleis JR, Bornemann KR, et al. Has the department of veterans affairs found a way to avoid racial disparities in the evaluation process for kidney transplantation? Transplantation. 2017;101(6):1191–1199. doi:10.1097/TP.000000000001377 [PubMed: 27482965]
- Peng RB, Lee H, Ke ZT, Saunders MR. Racial disparities in kidney transplant waitlist appearance in Chicago: is it race or place? Clin Transplant. 2018;32(5):e13195. doi:10.1111/ctr.13195 [PubMed: 29430739]

- Spector-Bagdady K, Tang S, Jabbour S, et al. Respecting autonomy and enabling diversity: the effect of eligibility and enrollment on research data demographics. Health Aff (Millwood). 2021;40(12):1892–1899. doi:10.1377/hlthaff.2021.01197 [PubMed: 34871076]
- 9. Park C, Jones MM, Kaplan S, et al. A scoping review of inequities in access to organ transplant in the United States. 2022;21(1):22. doi:10.1186/s12939-021-01616-x
- 10. Google Dataset Search "Transplantation". Accessed December 10, 2021. https://datasetsearch.research.google.com/search? src=0&query=transplantation&docid=L2cvMTFuZmJrMHd3dw%3D%3D
- 11. Google Dataset Search "Social Determinants of Health" Google. Accessed December 10, 2021. https://datasetsearch.research.google.com/search? src=2&query=Social%20Determinants%20of%20Health%20Data&docid=L2cvMTFuX3hwODh0 cw%3D%3D
- 12. Hamilton CM, Strader LC, Pratt JG, et al. The PhenX toolkit: get the Most from your measures. Am J Epidemiol. 2011;174(3):253–260. doi:10.1093/aje/kwr193 [PubMed: 21749974]
- Hendershot T, Pan H, Haines J, et al. Using the PhenX toolkit to add standard measures to a study. Curr Protoc Hum Genet. 2015;86(1):1.21.1–1.21.17. doi:10.1002/0471142905.hg0121s86 [PubMed: 26132000]
- 14. Organ Procurement and Transplantation Network History & NOTA. Accessed December 8, 2021. https://optn.transplant.hrsa.gov/about/history-nota/
- 15. United Network for Organ Sharing Data. Accessed December 7, 2021. https://unos.org/data/
- 16. Scientific Registry of Transplant Recipients. Data That Drives Development: The SRTR Database. Accessed December 11, 2021. https://www.srtr.org/about-the-data/the-srtr-database/
- 17. U.S. Renal Data System. 2020 Researcher's Guide to the USRDS Database. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; 2020.
- Healthcare Cost and Utilization Project (HCUP). Overview of the National (Nationwide) Inpatient Sample (NIS). Agency for Healthcare Research and Quality (AHRQ). December 20, 2021. https:// www.hcup-us.ahrq.gov/nisoverview.jsp#about
- 19. United States Census BureauUnderstanding and Using American Community Survey Data: What All Data Users Need to Know 2020.
- Centers for Medicare & Medicaid Services. CMS Data Element Library Fact Sheet. Centers for Medicare & Medicaid Services. Accessed December 29, 2021. https://www.cms.gov/newsroom/ fact-sheets/cms-data-element-library-fact-sheet
- 21. Johnson CL, Paulose-Ram R, Ogden CL, et al. National Health and nutrition examination survey: analytic guidelines, 1999–2010. Vital Health Stat 2. 2013;(161):1–24.
- Kulaylat AS, Schaefer EW, Messaris E, Hollenbeak CS. Truven health analytics MarketScan databases for clinical research in colon and Rectal surgery. Clin Colon Rectal Surg. 2019;32(1):54–60. doi:10.1055/s-0038-1673354 [PubMed: 30647546]
- 23. https://www.vizientinc.com/our-solutions/clinical-solutions/clinical-data-base
- Massarweh NN, Kaji AH, Itani KMF. Practical guide to surgical data sets: veterans affairs surgical quality improvement program (VASQIP). JAMA Surg. 2018;153(8):768–769. doi:10.1001/ jamasurg.2018.0504 [PubMed: 29617543]
- 25. National Surgical Quality Improvement Program ACS National Surgical Quality Improvement Program. American College of Surgeons. Accessed December 29, 2021. https://www.facs.org/ quality-programs/acs-nsqip
- Parekh J, Ko C, Lappin J, Greenstein S, Hirose R. A transplant-specific quality initiativeintroducing TransQIP: a joint effort of the ASTS and ACS. Am J Transplant. 2017;17(7):1719– 1722. doi:10.1111/ajt.14315 [PubMed: 28421672]
- 27. Geneviève LD, Martani A, Mallet MC, Wangmo T, Elger BS. Factors influencing harmonized health data collection, sharing and linkage in Denmark and Switzerland: a systematic review. PLoS One. 2019;14(12):e0226015. doi:10.1371/journal.pone.0226015 [PubMed: 31830124]
- United Network for Organ Sharing. UNOS to study data collection related to social determinants of health. Accessed January 20, 2022. https://unos.org/news/sdoh-data-collection/
- 29. Center for American Progress. Maximizing federal investments to address social determinants of health. February 14, 2022. Accessed April 3, 2022.

- 30. Tong A, Craig JC, Nagler EV, et al. Composing a new song for trials: the standardized outcomes in nephrology (SONG) initiative. Nephrol Dialysis Transplant. 2017;32(12):1963–1966. doi:10.1093/ndt/gfx288
- Plantinga L, Pastan S, Kramer M, McClellan A, Krisher J, Patzer RE. Association of U.S. dialysis facility neighborhood characteristics with facility-level kidney transplantation. Am J Nephrol. 2014;40(2):164–173. doi:10.1159/000365596 [PubMed: 25196018]
- Newman KL, Fedewa SA, Jacobson MH, et al. Racial/ethnic differences in the association between hospitalization and kidney transplantation among waitlisted end-stage renal disease patients. Transplantation. 2016;100(12):2735–2745. doi:10.1097/tp.000000000001072 [PubMed: 26845307]
- Flattau A, Olaywi M, Gaglio PJ, et al. Social barriers to listing for adult liver transplantation: their prevalence and association with program characteristics. Liver Transpl. 2011;17(10):1167–1175. doi:10.1002/lt.22357 [PubMed: 21656658]
- 34. Warsame F, Haugen CE, Ying H, Garonzik-Wang JM, Desai NM, Hall RK, Kambhampati R, Crews DC, Purnell TS, Segev DL, McAdams-DeMarco MA Limited health literacy and adverse outcomes among kidney transplant candidates. Am J Transplant Feb 2019;19(2):457–465. 10.1111/ajt.14994 [PubMed: 29962069]
- 35. Anderson L, File T, Marshall J, McElrath K, Scherer Z. New household pulse survey data reveals differences between LGBT and non-LGBT respondents during COVID-19 pandemic. United States Census Bureau Published November 4, 2021. Accessed January 4, 2022. https://www.census.gov/library/stories/2021/11/census-bureau-survey-explores-sexualorientation-and-gender-identity.html
- 36. Gold R, Bunce A, Cowburn S, et al. Adoption of social determinants of health EHR tools by community health centers. Ann Fam Med. 2018;16(5):399–407. [PubMed: 30201636]
- Cantor MN, Thorpe L. Integrating data on social determinants of health into electronic health records. Health Aff. 2018;37(4):585–590. doi:10.1377/hlthaff.2017.1252
- Patzer RE, Retzloff S, Buford J, et al. Community engagement to improve equity in kidney transplantation from the ground up: the southeastern kidney transplant coalition. Curr Transplant Rep. 2021;8(4):324–332. doi:10.1007/s40472-021-00346-x [PubMed: 36059891]

Data collection forms containing soci	Data collection forms containing social determinants of health variables (by data source)	data source)		
United Network of Organ Sharing (UNOS)	Scientific Registry of Transplant Recipients (SRTR)	United States Renal Data System (USRDS)	National Inpatient Sample (NIS)	American Community Survey (ACS)
<ul> <li>Deceased Donor Registration (8)</li> <li>Living Donor Follow-Up (2)</li> <li>Living Donor Follow-Up (2)</li> <li>Adult Transplant Candidate Registrations [kidney, pancreas, kidney/pancreas, intestine, liver, heart, lung, heart/lung] (10)</li> <li>Adult Transplant Recipient Registrations [kidney, pancreas, kidney/pancreas, intestine, liver, heart, lung, heart/lung] (5)</li> <li>Adult Transplant Recipient Follow-Ups [kidney, pancreas, kidney/pancreas, intestine, liver, heart, lung, heart/lung] (5)</li> </ul>	<ul> <li>General Deceased Donor Information (5)</li> <li>General Living Donor Follow-Up (2)</li> <li>Heart &amp; Lungs Transplant Candidates (7)</li> <li>Kidney &amp; Pancreas Transplant Candidates (7)</li> <li>Liver &amp; Intestines Transplant Candidates (7)</li> <li>Liver &amp; Intestines Transplant Candidates (7)</li> <li>Transplant Recipient Registrations [heart/lung, heart, lung, kidney, kidney/pancreas, pancreas, liver, intestine] (7)</li> <li>Transplant Recipient Follow-Ups [heart/lung, heart, lung, kidney/pancreas, pancreas, liver, intestine] (2)</li> <li>Liver &amp; Intestines Waitlist Status History (1)</li> </ul>	<ul> <li>OPTN Data Collection Worksheets (TCR, TRR, TRF) (9)</li> <li>CMS BERD Death Notification (2)</li> <li>CMS ESRD Death Notification (2)</li> <li>CMS ESRD Death Notification (2)</li> <li>USRDS Case Mix Adequacy Study (1990) (6)</li> <li>USRDS CAPD Peritonitis Survey (1990) (5)</li> <li>USRDS CAPD Peritonitis Survey (1990) (5)</li> <li>USRDS Case Mix Severity Study (1990) (5)</li> <li>USRDS Case Mix Severity Study (1990) (5)</li> <li>USRDS Data Validation Study (1989) (7)</li> <li>USRDS Data Validation Study (1989) (7)</li> <li>USRDS POR Quality of Life Study (9)</li> <li>USRDS Pediatric ESRD Growth &amp; Development Study (1990) (4)</li> <li>USRDS Renal Biopsy Study (1990) (3)</li> <li>USRDS Active Adipose Study (4)</li> <li>CMS-1450 Medicare Claim Form (7)</li> <li>CMS-1500 Medicare Claim Form (7)</li> </ul>	Core File (4)	2021 American Community Survey Questionnaire (20)
Centers for Medicare and Medicaid Services (CMS)	National Health and Nutrition Examination Survey (NHANES)	Truven Health Analytics MarketScan Research Database	Vizient Clinical Data Base	National Surgical Quality Improvement Program (NSQIP, TransQIP, VASQIP)
<ul> <li>Outcome and Assessment Information Set (7)</li> <li>Minimum Data Set (7)</li> <li>Long Term Care Hospital Continuity Assessment Record (6)</li> <li>Inpatient Rehabilitation Facility Patient Assessment Instrument (8)</li> <li>Hospice Item Set (6)</li> </ul>	<ul> <li>Demographics Data (13)</li> <li>Dietary Data (1)</li> <li>Questionnaire Data (11)</li> <li>Limited Access Data (4)</li> </ul>	• IBM MarketScan Database Dictionary Health & Productivity Management (4)	Vizient Clinical Data Base (7)	National Surgical Quality Improvement Program (NSQIP) (3) Transplant Quality Improvement Program (TransQIP) (10)
<i>Note:</i> Number in narentheces indicates number of	<i>Note</i> -Number in nerentheses indicates number of SDOH variables in each form with come variables included across multiple forms	included across multinle forms		

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Note: Number in parentheses indicates number of SDOH variables in each form with some variables included across multiple forms.

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# TABLE 1

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TABLE 2

Social determinants of health variables (by data source)

	United Network of Organ Sharing (UNOS)	Scientific Registry of Transplant Recipients (SRTR)	United States Renal Data System (USRDS)	National Inpatient Sample (NIS)	American Community Survey (ACS)
Access to health services			*		
Access to health technology					X
Annual family income			*		Х
Biological sex assigned at birth	Х	X	Х	Х	X
Birthplace	Х	X	Х		X
Citizenship/immigration status	Х	X	Х		Х
Current address	Х		х		X
Current age	Х	X	Х	Х	Х
Current employment status	Х	х	x		х
Discrimination					
Disparate health care quality			*		
Educational attainment—individual	Х	X	Х		Х
English proficiency					Х
Ethnicity and race	Х	Х	х	Х	Х
Food insecurity			*		х
Gender identity					
Health insurance coverage	Х	X	Х	Х	Х
Health literacy					
Health numeracy					
Job insecurity			*		Х
Marital status	Х	х	*		х
Occupational prestige			*		х
Sexual orientation					
Spirituality					
Wealth			*		Х
Zip code-derived variables $^{a}$	X	X	X		X
Total number of variables (% of variables included)	13 (46.4)	12 (42.9)	12 (42.9)	4 (14.3)	20 (71.4)

	Centers for Medicare and Medicaid Services (CMS)	National Health and Nutrition Examination Survey (NHANES)	Truven Health Analytics MarketScan Research Database	Vizient clinical data base	National Surgical Quality Improvement Program (NSQIP, TransQIP, VASQIP)	Data source inclusion rate (% of data sources)
Access to health services						0
Access to health technology						10
Annual family income		Х				20
Biological sex assigned at birth	Х	Х	Х	X	X	100
Birthplace		Х				50
Citizenship/immigration status		Х			Х	60
Current address		Х				40
Current age	Х	Х	X	X	Х	100
Current employment status	Х	Х	Х		Х	80
Discrimination						0
Educational attainment—individual		Х			Х	60
English proficiency	Х	Х				30
Ethnicity and race	X	х		x	X	06
Food insecurity		Х				20
Gender identity						0
Health insurance coverage	Х	Х	X	X	Х	100
Health literacy		Х				10
Health numeracy						0
Job insecurity		x				20
Marital status	X	Х				50
Occupational prestige	x	х				30
Sexual orientation		Х				10
Spirituality	X	Х				20
Wealth		Х				20
Zip code-derived variables <sup>a</sup>	х	X		Х	Х	80
Total number of variables (% of variables included)	12 (42.9)	22 (78.6)	4 (14.3)	7 (25.0)	10 (35.7)	

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<sup>2</sup>Zip code-derived variables consist of air quality index, concentrated poverty, and educational attainment—community. Inclusion of zip code was counted as three variables toward total.