National Institute of Diabetes and Digestive and Kidney Diseases

Kidney Interagency Coordinating Committee Meeting

September 19, 2025
9:00 a.m. to 12:00 p.m. EDT
Natcher Conference Center, Building 45, Meeting Room D
Bethesda, MD

Meeting Summary

Getting the Most Out of Existing Data to Improve Kidney Health

Welcome and Introductory Remarks

Susan Mendley, M.D., Program Director, KUH, NIDDK, NIH
Jenna Norton, Ph.D., M.P.H., Program Director, KUH, NIDDK, NIH
Robert Star, M.D., Director, KUH, NIDDK, NIH

Dr. Norton welcomed members and attendees to the NIDDK Kidney Interagency Coordinating Committee (KICC) meeting, which included both in-person and virtual attendees. She reminded participants that the KICC was mandated by Congress in 1987 to encourage cooperation, communication, and collaboration among all federal agencies engaged in kidney research and related activities. This mandate was in recognition of the need for better coordination of the federal response to chronic kidney disease (CKD). Dr. Norton noted that today's meeting will focus on getting the most out of existing data to improve kidney health. Dr. Mendley outlined the need for collaboration on this topic as many federal agencies have data collection efforts undertaken or ongoing that bear directly or indirectly on kidney health and the lives of people with kidney disease, including clinical, administrative, and patient-reported data collection. She commented that a goal of the meeting is to discuss how well aligned data are to understand gaps and overlaps as well as data elements may not reflect the underlying concepts consistently across sources.

Dr. Mendley introduced the following panel of attendees to discuss data sources on this topic:

- **N3C Renal Tenant**
  Hythem Sidky, Ph.D., National Center for Advancing Translational Sciences and Richard Austin Moffitt, Ph.D., Emory University of School of Medicine
- **Veteran's Health Administration**
  Csaba Kovesdy, M.D., University of Tennessee College of Medicine and Memphis Veterans Affairs Medical Center
- **Centers for Medicare & Medicaid Services (CMS): Innovation Center**
  Tom Duvall, M.B.A., CMS
- **CMS: Center for Clinical Standards & Quality**
  Golden Horton, M.S., CMS Quality Incentive Program, Darrick Hunter, CMS Dialysis Facility Care Compare, Stephanie Clark, M.D., M.P.H., M.S.H.P. and Melissa Dorsey, M.S., CMS
- **CMS: Medicaid**

Neha Shah, MSPH, CMS

- **Department of Defense (DoD)**
  Robert Nee, M.D. and Jim Oliver, M.D., Ph.D., DoD
- **Health Resources and Services Administration (HRSA) Scientific Registry of Transplant Recipients (SRTR)**
  Sarah Laskey, Ph.D., HRSA
- **Centers for Disease Control and Prevention: CKD surveillance, Behavioral Risk Factor Surveillance System, National Center for Health Statistics**
  Meda E. Pavkov, M.D., Ph.D., CDC
- **Agency for Healthcare Research and Quality**
  CDR Karen Chaves, M.H.S., Consumer Assessment of Healthcare Providers and Systems (CAHPS) Program; Pam Owens, Ph.D., Healthcare Cost and Utilization Project (HCUP); Jon Bakdash, Ph.D., Surveys on Patient Safety Culture® (SOPS®) Program, and Steven C. Hill, Ph.D., Medical Expenditure Panel Survey Publication Details, AHRQ
- **Census Bureau**
  Norm Johnson, Ph.D., Census Bureau
- **United States Department of Housing and Urban Development (HUD)**
  Veronica Helms Garrison, M.P.H., HUD
- **Department of Health and Human Services (HHS)**
  Kristen Honey, Ph.D., P.M.P., Chief Data Officer, HHS

Tom Duvall, MBA, Center for Medicare and Medicaid Innovation (CMMI), Centers for Medicare and Medicaid Services

Mr. Duvall commented that CMMI has tested and/or is in the process of testing four different payment models related to kidney and transplant care, detailing that each model has a website with detailed results. The websites include our independent evaluations conducted for each model looking at effects of cost, quality, and utilization relative to a matched comparison group as well as financial and quality results for each year of the model. Additionally, CMS posts data for researchers through the ResDAC site, which includes beneficiary identifiable data and provider files for researchers.

Csaba Kovesdy, M.D., University of Tennessee College of Medicine and Memphis Veterans Affairs Medical Center

Dr. Kovesdy commented that that The Department of Veterans Affairs (VA) maintains one of the largest and most comprehensive health data ecosystems in the world, enabling large-scale clinical, epidemiologic, and precision medicine research. At its core is the Corporate Data Warehouse (CDW)—an enterprise-level repository that integrates data from over 100 VA systems, primarily derived from the VistA electronic health record. The CDW provides near real-time access to clinical, pharmacy, laboratory, imaging, and administrative data for more than 20 million Veterans. Researchers access these data through the VA Informatics and Computing Infrastructure (VINCI), a secure, virtualized research environment that ensures compliance with privacy and data governance standards while offering analytical tools and computational resources. Complementing these platforms is the Million Veteran Program (MVP), a national research initiative with over one million consented participants linking genetic, lifestyle, clinical, and exposure data to CDW records—establishing one of the largest integrated biobanks for precision medicine in the world.

Supporting this infrastructure is the VA Information Resource Center (VIREC), established by VA Health Services Research & Development (HSR&D) as a national hub for data education, documentation, and user support. VIREC serves as a navigator, educator, and data-quality steward—guiding researchers

through access processes, governance requirements, and the nuances of data completeness and reliability. The VA's ecosystem also includes modernization initiatives such as mapping legacy VA data to the OMOP Common Data Model to enhance interoperability with external research networks, as well as linkages with external data sources like Medicare and the Department of Defense. Collectively, these integrated resources constitute a powerful data environment that supports longitudinal, population-based, and genomic research designed to improve the health and well-being of Veterans.

Robert Nee, MD, FACP, FASN, Nephrology Service, Walter Reed National Military Medical Center, Professor of Medicine, Uniformed Services University

Dr. Nee remarked that the Military Health System Data Repository (MDR) is the data warehouse for the Military Health System (MHS). It is the most comprehensive source of MHS data available. It contains a unique person identifier allowing patient-level files to be linked across data sources. Data capture in the MDR is dependent on the Tricare plans. Under the Tricare Prime plan (HMO model), patients are given priority care in Military Treatment Facilities (MTFs) where they receive most of their routine care. They can be referred out to the civilian network if needed. In this case, the MDR provides EHR data for encounters in the MTFs to include demographics, diagnoses, procedures, labs, vital signs, prescriptions, etc. There are also claims data for care in private civilian facilities. Under the Tricare Select plan (PPO model), patients primarily receive care from civilian providers, but they can also use MTFs on a space-available basis. The MDR provides claims data, prescriptions and EHR data for MTF encounters only. Medicare-eligible beneficiaries receive most of their care in the private sector but can also utilize MTFs on a space-available basis. In this case, there are limited claims and prescription data, and EHR data for MTF encounters only.

Strengths of the MDR include:

- greater generalizability to the U.S. population less than 65 years of age, as compared to data derived from Medicare, private payer claims, or institutional registries;
- the MDR allows for large study cohorts with longitudinal data;
- the MHS uses an integrated, global EHR system called GENESIS;
- the MHS is a single-payer healthcare system, and its data are often used to model the effects of universal health insurance in the U.S.;
- the MDR allows for comparisons of practice patterns and resource utilization between direct vs. private sector care.

However, limitations of the MDR include:

- lack of detailed clinical information, inherent in an administrative claims database;
- EHR data are only available in the direct care environment;
- missing race and ethnicity data (has improved in recent years);
- statistical modeling needs to be adjusted for the environment of care;
- population mobility in the U.S. Department of War limits geographical analyses.

*Meda E. Pavkov, M.D., Ph.D., CDC***:** CKD surveillance, Behavioral Risk Factor Surveillance System, National Center for Health Statistics

Dr. Pavkov noted that the goal of her agency is to promote kidney health as mandated, commenting that the CDC's CKD Initiative conducts surveillance, epidemiology and health outcomes research, developing awareness and educational materials for health care professionals and the larger public. The CKD Initiative maintains a comprehensive surveillance system on pre-end-stage kidney disease in the U.S. on the CDC website (KDSS | Home | CDC), which continuously documents the burden of kidney disease, its modifiable risk factors, outcomes, inequalities, and quality of care.

Together with NIDDK, the CKD Initiative provides funding for NHANES measures of kidney markers, including serum creatinine, serum cystatin C, urine albumin and creatinine, and a kidney related questionnaire. For this purpose, CDC's CKD Initiative obligated $2.9 million in FY2026 funds. This will fund the NHANES kidney component for the 2025-2027 cycle. Through the National Center for Health Statistics (NCHS) and in collaboration with NIDDK, the CDC provided additional funding for data linkage between U.S. Renal Data System and NHANES 1999-2018, which will be continuously updated.

She detailed that both the Behavioral Risk Factor Surveillance System and the National Health Interview Survey include a question on kidney disease, but no laboratory data are being collected as part of these surveys. Because CKD awareness remains very low, with one in 10 adults not being aware of having the disease, CDC is not using these interview surveys to estimate the national prevalence of CKD or CKD awareness. Therefore, NHANES is the only nationally representative surveillance system that allows to track the epidemiology of kidney disease in the U.S. NCHS, however, has experienced a continuous decline in the response rate, particularly for the survey examinations, which is a concern for the future representativeness of NHANES data. For this reason, the CKD Initiative is exploring other data sources, such as electronic medical records, Porter Novelli Styles Surveys, and existing registries. The Porter Novelli Styles Surveys are bi-annual, nationally representative web surveys of multiple target groups—adults, youth, mothers, policy makers, and health care professionals. Components include:

- ConsumerStyles, including ~6,000 adults to assess beliefs and behaviors regarding various health topics.
- YouthStyles: ~800 youth ages 12–17 to explore relationships, influences, behaviors, or media use.
- DocStyles: ~1,000 family practitioners and internists to assess patient interactions and sources of health information.
- Others: Surveys of mothers, market research studies, and focus groups/expert interviews, etc.

For non-representative data sources, CDC is working on statistical methods that allow us to make inferences that are representative.

Following a short break, KICC meeting participants discussed how to leverage data to answer questions.

Dr. Mendley concluded the meeting following agency updates from attendees.