Kidney Interagency Coordinating Committee Meeting
March 19, 2026
9:00 a.m. to 12:00 p.m. EDT
Natcher Conference Center, Building 45, Meeting Room D
and by webinar
Bethesda, MD/MS Teams

Meeting Summary

Viewing the Extent of Kidney Diseases Using Federal Data

Introductory Remarks

Robert Star, M.D., Susan R. Mendley, M.D., and Debbie Gipson, M.D., M.S., Division of Kidney, Urologic, and Hematologic Diseases, National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institutes of Health (NIH)

Dr. Mendley opened the meeting, noting that this meeting will be focused on viewing the extent of kidney diseases using federal data, and thanked participants for attending. Following opening comments by Drs. Star and Mendley, Dr. Mendley introduced the speakers and facilitated discussion.

Levels of publicly available data and examples of available data sets

Shirley Fung, DHSc, MPH, MSMR
Team Leader – MIPS Scoring, Data Analytics, and Operations
Division of Clinician Quality
Quality Measurement and Value-based Incentives Group (QMVIG)Center for Clinical Standards and Quality (CCSQ)
Centers for Medicare & Medicaid Services (CMS)

Dr. Fung's presentation focused on the levels of publicly available data and examples of available datasets. She discussed three levels of publicly available government data—Data.gov, HealthData.gov, and Data.cms.gov—and demonstrated how they can be used to explore healthcare datasets. Data.gov serves as the largest open data portal, hosting hundreds of thousands of datasets across multiple sectors with robust filtering and machine-readable formats. HealthData.gov focuses specifically on health-related data from HHS agencies, offering extensive datasets on topics like Medicare, public health, and health equity, along with tools to refine and navigate the data inventory.

The presentation then highlights Data.cms.gov, CMS's dedicated open data portal, which provides datasets related to Medicare, Medicaid, and other CMS programs. It demonstrates how users can search, filter, and interact with datasets—such as Medicare Part D Prescriber data—using built-in interactive tools to extract meaningful insights like prescribing patterns, utilization, and costs. Overall, the resources aim to support data-driven decision-making and advance efforts in areas like kidney disease prevention and treatment.

Public data and the Virtual Research Data Center (VRDC)
Andrew Shatto
Director, Research Data Development Group (RDDG)

Ha Abrams
Information Technologist
Information Products and Analytics Group (IPAG)
Office of Enterprise Data and Analytics (OEDA)
Centers for Medicare & Medicaid Services (CMS)

Andrew Shatto and Ha Abrams presented information on public data tools on data.CMS.gov. Dr. Abrams provided the following look-up tools for hospitals and providers who treat Medicare enrollees:

- Medicare Inpatient Hospital Look-up Tool: allows the user to look up a Medicare hospital facility and view associated inpatient services
- Medicare Physician & Other Practitioner Look-up Tool: allows the user to look up a Medicare Part D prescriber and view their associated drugs
- Medicare Part D Prescriber Look-up Tool: allows the user to look up a physician or practitioner and view their associated services
- Medicare Revalidation List: allows the user to look up the revalidation due date for Medicare provider enrollment
- Provider Opt-Out Affidavits Look-up Tool: allows the user to look up a provider who has opted out of Medicare

Additionally, she provided select mapping tools and dashboards:
- Medicare Enrollment Dashboard: provides the most current counts of Medicare beneficiaries with hospital/medical coverage and prescription drug coverage by geographic area
- Market Saturation Tools (state/county + core based statistical area): provides the ability to monitor market saturation to help prevent potential fraud, waste, and abuse
- Drug Spending Dashboards (Medicare Part B + Medicare Part D + Medicaid): present spending information for Medicare Part D drugs, Medicare Part B drugs and drugs paid through the Medicaid program

CMCS data - Adult and Child Core Sets
Deirdra Stockmann, Ph.D., MUP
Director, Division of Quality and Health Outcomes
Center for Medicaid and CHIP Services
Centers for Medicare & Medicaid Services (CMS)

Dr. Deirdra Stockmann presented on Medicaid and Children's Health Insurance Program (CHIP) data including administrative data and the Child and Adult Core Sets of Health Care Quality Measures. The Transformed Medicaid Statistical Information System (T-MSIS) is the most comprehensive national data set on Medicaid and CHIP beneficiaries, providers, service utilization, managed care, expenditures, and third-party liability for Medicaid and CHIP. T-MSIS data are available to researchers as **T-MSIS Analytic Files (TAF)** to support analysis, research and data-driven decisions on key dimensions of Medicaid and CHIP.

The Medicaid and CHIP Core Sets of Health Care Quality measures, commonly referred to as the Child and Adult Core Sets, are sets of standardized health care quality measures that CMS and states can use to measure the quality of care delivered to over 70 million Medicaid and CHIP beneficiaries and improve

quality and health outcomes. States submit state-level data to CMS annually, and CMS publicly publishes data on measures reported by at least 25 states that meet data quality standards on the Core Set Data Dashboard. As required by Social Security Act sections 1139A and 1139B, the Core Sets are updated annually, in consultation with stakeholders.

Using and Extending CMS Data for Surveillance of Chronic Kidney Disease
Linda J. Andes, Ph.D.
Mathematical Statistician
CCDPHP/DDT
Centers for Disease Control and Prevention

Dr. Linda J. Andes presented two projects underway at the Division of Diabetes Translation at CDC using CMS Medicare data. Both initiatives leverage CMS Medicare data to advance the understanding and surveillance of diabetes and related health conditions among Medicare beneficiaries.

The first project, "Diabetes and Related Comorbidities and Complications among Medicare Beneficiaries Enrolled in Fee-For-Service and Medicare Advantage, 2017-2023" compares prevalence of diabetes and 16 related comorbidities among Fee-for-Service and Medicare Advantage beneficiaries with diabetes. Chronic kidney disease is higher among beneficiaries enrolled in Medicare Advantage which underscores the importance of including this population in surveillance efforts for CKD.

The second project uses linked electronic health records and claims data from Truveta to identify patients with lab-confirmed early stage CKD but without corresponding diagnosis codes in their records. By analyzing the patients' linked claims data, the team plans to develop a machine learning model capable of predicting CKD based solely on features available in claims data. This innovative model will be applicable to populations that possess claims data but lack laboratory results, such as Medicare and/or Medicaid beneficiaries.

Quality measure process and current kidney measures in value-based programs
Stephanie L. Clark MD, MPH, MSHP
Medical Officer
Division of Quality Measurement (DQM)
Quality Measurement and Value-Based Incentives Group (QMVIG)
Center for Clinical Standards and Quality (CCSQ)
Centers for Medicare & Medicaid Services (CMS)

Dr. Stephanie Clark's presentation's focused on the quality measure process and current kidney measures in value-based programs. She began with the difference between quality measures and quality metrics. Quality measures are standards for measuring the performance and improvement of population health or of health plans, providers of services, and other clinicians in the delivery of health care services while quality metrics are the specific, numerical data points that indicate how well a goal is being met or how well a process is performing. Quality metrics are often used in local quality improvement efforts. Quality measures are used in health care quality measurement to assess a change in quality related to an aspect of health care delivery such as health outcomes, clinical processes, patient safety, efficient use of health care resources, care coordination, patient engagement in their care, patient perceptions of their care, or population and public health. The purpose of quality measures and quality measurement is to provide a more comprehensive picture of the overall quality of health care. More information can be found at https://mmshub.cms.gov/blueprint-measure-lifecycle-overview.

She then described the measure development process which consists of five distinct but inter-related steps including Measure Conceptualization, Measure Specification, Measure Testing, Measure Implementation, and Measure Use, Continuing Evaluation, and Maintenance. Two measures currently in the Merit-based Incentive Payment System (MIPS) program are then described as examples of currently active CKD-related measures. The first is the Kidney Health Evaluation measure, and the second is the Adult Kidney Disease: Angiotensin Converting Enzyme (ACE) Inhibitor or Angiotensin Receptor Blocker (ARB) Therapy measure. The data submitted to CMS for both of these measures does not include lab values, eGFR, or medications. With that in mind, development of a future CKD quality measures would need to be thoughtful in terms of structure and what data elements are submitted to CMS.

Surveying Chronic Kidney Disease in the United States
Meda E. Pavkov, M.D., Ph.D.
Lead, Epidemiology Team

Hui Xie, Ph.D.
Mathematical Statistician
Centers for Disease Control and Prevention

Dr. Meda Pavkov, Lead for Epidemiology Team, and Hui Xie, Mathematical Statistician at the CDC, presented information on surveying chronic kidney disease in the United States. Dr. Pavkov commented that NHANES is the only nationally representative surveillance system that allows to track the epidemiology of kidney disease in the U.S. 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 FY2025 funds. This will fund the NHANES kidney component for the 2025-2027 cycle. Through NCHS and in collaboration with NIDDK, CDC provided additional funding for data linkage between U.S. Renal Data System and NHANES 1999-2018, which will be continuously updated. The NHANES response rate, however, has been declining steadily from 77% in 2009-10 to 20% in 2021-23 surveys (examination response rate). These unfavorable trends raise concerns about the reliability and viability of NHANES after 2028 and the question whether further investment in NHANES can be justified.

The team detailed several advantages of NHANES:

- The only nationally representative survey with laboratory data on kidney markers and some of the CKD risk factors
- Markers are standardized and methodology is consistent over time
- Linkages with other national data (NIS, CMS, USRDS)
- Biorepository

However, several disadvantages of this program were also noted:

- Cross-sectional
- Time lag in data release
- Access for certain linkages is available through RDC only
- Participant recruitment remains a challenge

Dr. Pavkov commented that alternative solutions considered by CDC include Porter Novelli style surveys, electronic medical records (IQVIA, TRUVETA, Marketscan, Epic), NCHS Rapid surveys, claims data in combination with survey data.

Dr. Xie also commented on additional disadvantages in terms of measurement sustainability, noting that

some key measurements have been discontinued and may be further reduced in future cycles due to logistical complexity and budget constraints. For example, the 2-hour plasma glucose (2hPG) test was dropped after 2016, limiting the application of standard diagnostic criteria and likely leading to underestimation of prediabetes and diabetes prevalence, particularly among high-risk populations.

He noted that, in order to address these limitations, advanced statistical and machine learning approaches could be leveraged to integrate NHANES with complementary data sources (e.g., EHRs, claims, and rapid surveys). Such data fusion methods can improve estimation accuracy, compensate for missing measures, and enhance surveillance of kidney disease and its risk factors.

Meeting participants then discussion how well agencies are describing the breadth of kidney disease, how agencies could better capture the full impact, and future opportunities in this area.

Following the discussion, meeting participants provided agency updates.

Dr. Mendley commented that the next KICC meeting will be held on September 25, 2026, in NIH Building 31, 6C, Rooms A&B. The meeting was then adjourned.