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Advancing the Mission of the US Renal Data System: Challenges and Opportunities



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Overall US Renal Data System Mission

The US Renal Data System (USRDS) was established in 1988 to collect and analyze information on the incidence, prevalence, morbidity, and mortality of end-stage renal disease (ESRD) in the United States.¹ Today it has 6 goals: to characterize the patient population; report on the incidence, prevalence, and mortality rates and trends over time; analyze the effects of modality of treatment; describe treatment trends and patterns in chronic kidney disease (CKD), highlight contemporary issues of national importance to the CKD/ESRD population (eg, transitions from CKD to ESRD and early mortality after initiation of dialysis) and opportunities for more focused study; conduct economic analyses of the costs of CKD and ESRD; and make data available to investigators for research studies.¹ Since its inception, the USRDS has expanded the depth and breadth of its content and the sources of data used to fulfill its reporting and research support activities.

As the USRDS enters its fourth decade, a critical examination of its mission, vision, and focus is in order. We believe that the mission of the USRDS to document the impact of kidney disease on the US population and support research and policy initiatives designed to improve the care of individuals with kidney disease is as vital today as it was in 1988. The Annual Data Report (ADR) is the authoritative source of data about the magnitude, characteristics, treatment, and costs of care of the CKD and ESRD populations in the United States. In addition, data supplied by the USRDS have been used to support a wide range of research efforts, resulting in more than 50 peer-reviewed publications per year.²

To preserve the enormous resource the USRDS has become and to increase its value to the kidney community, we need to carefully assess current sources of data and develop new ones to adapt to the evolution in delivery and reimbursement of care for patients with CKD and ESRD. In addition to advocating for data integrity and relevance, the USRDS will focus on improving data presentation, interpretation, and availability.

Challenges and Opportunities

The USRDS must evolve to incorporate new data sources and form new partnerships to ensure that changes in payment models and policies do not reduce the availability of timely and accurate data. For example, the development and implementation of payment models that rely on capitated payment rather than on traditional fee for service, such as Medicare Advantage and Kidney Care Choices, could erode the granularity and accuracy of reporting of

costs and use of therapeutic interventions because services are no longer reimbursed individually.

However, USRDS is working with the Centers for Medicare & Medicaid Services and the Center for Medicare and Medicaid Innovation to devise methods to ascertain patients' participation in Medicare Advantage and other alternative payment models to track uptake of these models and determine how and whether patients in different payment systems may differ in their clinical characteristics, use, and outcomes. Incorporation of such information into ESRD-related data sets could provide an opportunity to better understand variations in clinical practice and how they are associated with outcomes.

Changes in policy or delivery of care also have the potential to transform clinical practice patterns in ways that may affect traditional surveillance metrics that have become the cornerstone of ESRD quality reporting. For example, the recent extension of Medicare reimbursement to cover outpatient dialysis for acute kidney injury (AKI) in 2017 may shift the timing of dialysis initiation for ESRD, and deaths that occur during dialysis for AKI may affect rates of early dialysis mortality. The very definition of dialysis initiation and early dialysis mortality may experience "data creep" when the boundary between ESRD and prolonged dialysis for AKI becomes increasingly blurred. These issues are particularly challenging because there is currently no data source that identifies individuals receiving outpatient dialysis for AKI and the point at which they transition to ESRD. Our initial focus will be on examination of rates of outpatient dialysis for AKI and related outcomes, including recovery, ESRD, and death before ESRD among Medicare fee for service beneficiaries, but we are also working to develop new data sources and to use multiple sources to generate meaningful data through examination of subsets of the overall AKI population receiving outpatient dialysis.

Annual Data Report

We have re-envisioned the content and presentation of the ADR. The most immediately noticeable changes will be in its appearance. The 2020 ADR is built on a brand new platform and is presented in a novel format. The guiding principles in the ADR redesign were enhancing the user experience, improving ease of use, and making the content customizable to readers' needs and preferences. The ADR has been transformed from a static document to a dynamic and interactive exercise, resulting in a richer, more efficient, and easily tailored user experience on a computer, tablet, or smartphone. The relationship between graphical

content and text has been reimaged so that tables and figures take center stage, with descriptive text juxtaposed for easy reference. Figures can be manipulated by the reader to display the data of most interest. For example, many figures allow the user to choose to see raw (unadjusted) counts or rates or adjusted rates or to toggle between the 2 to see clearly the extent to which changes over time are related to changes in demographic characteristics of the population. In other cases, readers can choose to see data stratified by different patient characteristics or to show data within subgroups of interest with automatic rescaling of axes as necessary for optimal viewing, and users can download figures that they have customized.

ADR content has also been updated and will continue to evolve in coming years. We will introduce new contemporary topics while maintaining focus on key surveillance functions. We have identified several of these emerging topics and overarching goals that we plan to address:

- Assessing the effects of policy changes on economic and patient-centered outcomes
- Tracking the uptake of new therapeutics and assessing their clinical and economic impact
- Focusing on racial and ethnic disparities in incidence and prevalence of CKD and ESRD and in access to treatment of these conditions
- Examining the implementation of new methods of dialysis delivery or new dialysis modalities and their effects on outcomes
- Expanding the focus on the patient experience of CKD and ESRD by adding a chapter in the ADR on the patient experience
- Leveraging Hennepin Healthcare Research Institute's experience administering the Scientific Registry of Transplant Recipients to improve the presentation of data in the ADR transplant chapter and to increase stakeholders' access to data on kidney transplantation

For the 2020 ADR, the coronavirus disease 2019 (COVID-19) pandemic presented an unexpected and urgent new focus of surveillance and investigation. Although traditional sources of data used in preparation of the ADR inherently include an 18-month lag, we have used ESRD-specific quarterly update files to examine changes in mortality, hospitalization, and onset of ESRD during the period of the pandemic. In future ADRs, we will present more detailed information about treatment and outcomes related to COVID-19 among patients with ESRD.

Improving Data Accessibility for the Kidney Community

A core function of the USRDS is to make data available to the kidney community for research purposes. We have streamlined data request processes to expedite delivery of standard analysis files and merged data requests. In

addition, we have completely revamped the online data query tool (previously known as RenDER) to improve its user friendliness. Its interface is now far nimbler and more intuitive, with enhanced customizability. In addition to permitting easier searching for the data of interest, the new system allows users to choose the form in which the output is displayed and exported. This new system has a new name: DESKRIBE (Data Extraction System for Kidney-Related Information & Basic Epidemiology).

Conclusions

The USRDS now has a more modern website, ADR, and data extraction system. Over the coming years, our core emphasis on basic epidemiology of CKD and ESRD will be accompanied by focused analyses on evolving health care policy, new diseases and therapeutics, the patient experience, and disparities in care and outcomes. Other USRDS Coordinating Center activities will emphasize service to the kidney community. This combination will result in the delivery of accurate, relevant, and customized data in a user-friendly and streamlined manner and will equip the USRDS to meet future challenges in a rapidly changing health care landscape.

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