

Patient Access Initiative 2023 Meeting Summary

The Patient Access Initiative hosted its inaugural summit in 2023. The summit convened a broad group of stakeholders, including patients, advocates and industry leaders. Former Health and Human Services Secretary Alex Azar was the plenary speaker for the event. Discussions centered around policy solutions to encourage early diagnosis and improve care for kidney patients.

Screening and Testing

Nine out of 10 people with chronic kidney disease are unaware they have it. Advocates noted that many people with chronic kidney disease die from cardiovascular complications before even getting a diagnosis.

CHALLENGES



Lack of clear and actionable instruction for health care providers



Poorly reimbursed genetic counselors

SOLUTIONS



Develop U.S. Preventive Services Task Force recommendations on screening for chronic kidney disease



Ensure that Medicare directly reimburses genetic counselors by passing the Access to Genetic Counselor Services Act

Patient Education and Navigation

Patient advocates identified patient education and navigation as major challenges. Many people at high risk aren't aware of their risk factors and don't know when to ask for screening for kidney disease.

CHALLENGES



Unclear coverage of genetic testing



Health disparities, which result in lack of access to clinical trials, patient education and treatment options

SOLUTIONS



Expand physician education programs



Partner with community organizations to develop culturally competent educational materials

The Food and Drug Administration Approval Process

Patients and providers noted that many challenges stem from the U.S. Food and Drug Administration.

CHALLENGES



High rejection rates for chronic kidney disease treatments



Lack of input from patients and advocates at the FDA

SOLUTIONS



Ensure sufficient nephrology expertise on the Cardiovascular and Renal Drugs Advisory Committee



Include a kidney disease patient advocate as a permanent member of the Cardiovascular and Renal Drugs Advisory Committee

Coverage Issues

Coverage issues arise in several areas, including the Center for Medicare and Medicaid Innovation payment models and commercial health plan coverage.

CHALLENGES



Lack of financial incentives for commercial insurance to prioritize early treatment



Challenges for patients and providers as they navigate Center for Medicare and Medicaid Innovation models



Limited access to treatments because of prior authorization, step therapy and high cost-sharing

SOLUTIONS



Support value-based payment models so insurers can prioritize preventive care and improved health outcomes



More opportunities for patients and providers to weigh in



Utilization management reform to ensure timely access to treatment

With resolute policymaking and continued advocacy, stakeholders can shape a brighter future for people living with chronic kidney disease.

The Patient Access Initiative focuses on the patient and caregiver burden, regulatory challenges, and health insurance design to better understand and address issues faced by the kidney patient community.

The summit was made possible thanks to generous support from Leadership Sponsors Travers Therapeutics, Novartis Pharmaceuticals Corporation, Champion Sponsors Horizon Therapeutics plc and Vertex Pharmaceuticals, Inc. and Supporting Sponsors Alexion, AstraZeneca Rare Disease and CSL Vifor.