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Overcoming Diagnostic Disparities in Kidney Disease: A Call to Action

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The following editorial is written by the 2024 cohort of the ISN Emerging Leaders Program, a global community of emerging leaders in kidney care, all dedicated to advancing early diagnosis and timely treatment of kidney disease.

Chronic kidney disease (CKD) disproportionately affects low-income countries at 11% to 12% as compared with 9% to 10% in high-income settings. CKD is projected to become the fifth leading cause of death globally by 2040.[1] Unfortunately, the majority are undiagnosed. For example, in an extensive Chinese database study, 72% of people with stage 3 CKD were not formally diagnosed.[2] A recent survey conducted in a CKD hotspot in India revealed that 9 out of 10 individuals with CKD were newly diagnosed.[3] Early diagnosis is critical for initiating interventions to alter the disease course and thereby minimize complications, maintain quality of life, and reduce health care costs associated with advanced kidney disease treatments such as dialysis or transplantation.[4]

This is of particular concern in low-income countries, where only 26% report being able to offer kidney replacement therapy to at least half of the patients who need it.[5] Unfortunately, early diagnosis is hampered by limited access to diagnostic tools. These tools can be conceptualized in tiers based on health care system maturity. First-tier diagnostics include serum creatinine, estimated glomerular filtration calculation, urine dipstick testing, and urine albumin- or protein-to-creatinine ratio measurement. After kidney disease is identified, further investigations with more resource-intensive advanced-tier diagnostics —such as kidney biopsy or genetic evaluation—can help determine the underlying cause and guide appropriate management. At present, there are major inequities in access to both first-tier and advanced-tier diagnostics requiring targeted implementation strategies.

Biochemical Testing: The First Step in Early Diagnosis

Global Gaps in Biochemical Testing for Kidney Health

Access to basic biochemical markers of kidney health, such as blood and urine tests, is a cornerstone of early detection and management of CKD. However, data from the ISN Global Kidney Health Atlas project[6,7] highlights a global disparity in access to these essential diagnostics. Access is particularly limited in low- and middle-income countries: only one-third had access to serum creatinine testing in primary care; estimated glomerular filtration and quantitative proteinuria assessments were rarely

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available, and only a few had urine test strips accessible. Even in high-income countries, access is not universal—only 58% had access to urine albumin-to-creatinine ratio or urine protein-to-creatinine ratio testing in primary care, indicating that diagnostic gaps exist across all income levels.

Barriers to Diagnostic Access: A Multi-Level Perspective

Several barriers contribute to this disparity. At the disease level, CKD remains asymptomatic for most of its trajectory, which may delay testing and diagnosis.[8] At the individual level, limited awareness and health literacy can produce further delays.[9] Cost is a major factor, especially where out-of-pocket payments are high.[5] Clinician-level barriers include insufficient training and lack of decision support tools to guide testing in primary care.[S1,S2] At the health care system level, inadequate infrastructure and staffing, and lack of standardized testing protocols, hinder reliable service delivery.[S3] Governmental factors such as insufficient funding, weak policy frameworks, and lack of prioritization of kidney disease diagnostics further exacerbate the problem.

Solutions Across the Care Continuum

To address these issues, multilevel strategies are required. At the community level, education programs can increase awareness and encourage early testing.[S4,S5] Clinician-focused interventions, including targeted training and clinical decision support tools, may improve diagnostic accuracy.[S1,S6] Health care system improvements such as investing in laboratory infrastructure and systematic disease detection programs, particularly for high-risk populations, can enhance testing capacity.[6,S7] Government policy reforms, such as funding subsidies, national screening programs, and regulatory support, are likely to have the highest impact.[5,S8]

Country-Level Success Stories

Successes worldwide clearly demonstrate the value of a systematic approach. Taiwan's national CKD prevention program, launched in 2001 and funded through its National Health Insurance, uses a targeted risk-factor based approach, and integrates CKD testing and management into routine care via a tiered referral system through a combination of national policies, pay-for-performance programs, multidisciplinary teams, and standardized follow-up procedures. Over a decade, it significantly delayed progression to end-stage kidney disease and reduced dialysis incidence rates by 15% to 20% among program participants.[S7] Uruguay's National Renal Healthcare Program, implemented in 2004 with government support, mandated routine CKD testing in primary care and linked reimbursement to early detection metrics. This initiative led to improved nephrology referral rates and better blood pressure control among patients with CKD.[S8]

Kidney Biopsy: A Critical Tool for Precision Diagnosis

Global Gaps in Access to Kidney Biopsies

Kidney biopsies help differentiate between various glomerular, tubulointerstitial, and vascular kidney diseases; identify disease activity or chronicity; and help assess prognosis—influencing both immediate and long-term management strategies. Despite its importance, according to the ISN-Global Kidney Health Atlas, many regions either do not perform biopsies at all or do so with major limitations.[S9] For instance, in Nigeria, logistical barriers and shortages of trained staff mean that biopsies are infrequent or performed without optimal equipment.[S10] In Nepal, some centers rely solely on light microscopy because of the absence of immunofluorescence or electron microscopy, thus reducing diagnostic accuracy.[S11] With the evolving discoveries of antigens, the role of immunofluorescence in diagnosis and management, cannot be overemphasized.[S12]

Infrastructure and Workforce Limitations

The successful implementation of a kidney biopsy program requires substantial resources. This includes trained personnel to perform the procedure safely, sterile procedural facilities, and access to comprehensive histopathological analysis, including light microscopy, immunofluorescence, and electron microscopy. Importantly, renal pathologists trained to interpret these samples accurately are often lacking in low and middle-income countries, creating a bottleneck in diagnosis.[S13]

Global Initiatives and Local Innovations

To address these gaps, global initiatives have emerged. Programs such as the ISN Sister Renal Centre initiative and the ISN Educational Ambassador program foster partnerships between resource-limited centers and well-equipped institutions, enabling knowledge exchange, capacity building, and providing tailored, hands-on training and education.[S14] In India, while kidney biopsies are mostly limited to tertiary centers, partnerships with private laboratories and investments in telepathology are improving turnaround times. Some private diagnostic chains offer subsidized biopsy services, supported in part through government insurance schemes.[S15] Training programs for nephrologists, technicians, and pathologists must be scaled up.

Engagement with industry could also support affordable access to biopsy kits and reagents.

Genetic Testing: Unlocking the Future of Precision Nephrology

Importance of Genetic Testing in Kidney Disease

Obtaining an accurate genetic diagnosis helps to end the diagnostic odyssey for many patients and prevents them from unnecessary invasive investigations.[S16] Variant-level genetic information informs prognosis, guides treatment decisions, better prepares individuals for kidney transplantation, informs reproductive decisions, and can benefit others in the family via cascade testing.[S17]

Global Disparities and Common Barriers

However, access to genetic testing varies greatly across countries—ranging from no access at all, including in some high-income countries, to its use as a first-line diagnostic tool or even for newborn screening in others.[S18] Many countries face challenges in providing clinical genetic testing services and integrating genetic evaluation into their current health care system.[S19] Common barriers include the lack of infrastructure, trained laboratory staff, comprehensive bioinformatics pipelines, genetic literacy among health care professionals, expertise to correctly interpret the results, and genetic counsellors or geneticists to provide proper genetic counselling. Cost is an important issue because in some countries, patients need to pay out-of-pocket and genetic testing is not covered by insurance. Lack of funding is a major issue in initiating and substantiating genetic service development. Though government policies play a pivotal role in driving health care development, precision medicine initiatives are virtually absent or inadequately implemented in many regions.[S20,S21]

Strategic Solutions and Prioritization

To improve access to genetic testing, a systematic approach is essential. At the individual level, engaging local communities can help identify barriers to screening among ethnic, racial, linguistic, geographic, and gender minorities, thereby enabling tailored solutions. Incorporating genetic testing into health coverage increases incentives for individuals and families to pursue evaluation. In resource-limited settings, testing should be prioritized for individuals with a high pretest probability of a disease-causing variant, such as early-onset disease, syndromic features, extrarenal involvement, or a family history of kidney disease. Clinicians benefit from genomic training to recognize monogenic kidney disease, refer appropriately, choose cost-effective tests such as gene panels over whole exome or genome sequencing, interpret results, and apply findings in practice.

Scaling Access Through Policy and Partnerships

Public health policies and funding are crucial for establishing local genetic testing infrastructure. The Hong Kong Genome Project, a government-funded initiative, exemplifies efforts to implement precision medicine, develop genomic services, and build local expertise.[S22] Creating regional databases and collaborative networks, along with international partnerships, will further accelerate progress toward precision nephrology.[S23]

Innovations and Implementation Prioritization

The Future: Point-of-Care Testing, Artificial intelligence, Digital Platforms, and Public Private Partnership

Point-of-care devices for serum creatinine, dipstick proteinuria, and hemoglobin testing are increasingly accessible and can decentralize early detection to remote and underserved areas.[S24,S25] Artificial intelligence–enhanced histopathology is also emerging, with algorithms aiding pattern recognition and classification of glomerular diseases, thus reducing interobserver variability and optimizing pathologist workloads.[S26,S27] Portable laboratory platforms capable of basic biochemical analysis or even digital slide scanning can facilitate faster diagnosis in rural settings. These advancements, though promising, require alignment with health system workflows, regulatory approvals, and training programs.[S28,S29]

Public-private partnerships play a pivotal role in scaling these innovations. Collaborations with diagnostic companies can support subsidized pricing for point-of-care kits, biopsy reagents, or genetic testing equipment; and partnerships with digital health firms can strengthen telepathology and remote diagnostics infrastructure. Examples include mobile diagnostic vans funded jointly by state governments and nongovernment organizations in India,[S30] and cloud-based pathology platforms piloted in Sub-Saharan Africa through academic-industry alliances.[S31]

Implementation Prioritization Through a Tiered Strategy

Health systems need to prioritize implementation strategies. First-tier diagnostic tests are foundational to diagnosis and should be universally available. Advanced-tier diagnostics such as kidney biopsy and genetic testing are best prioritized in settings where basic testing is already integrated, and infrastructure and trained

personnel are available or actively being developed. This tiered approach allows for resource allocation aligned with local capacity, helping health systems progress incrementally toward precision nephrology.

In conclusion, overcoming diagnostic disparities in kidney disease demands a clear vision for the future; one in which every patient receives timely, accurate diagnosis and equitable, high-quality care regardless of geographic location, gender, race, ethnicity, or socioeconomic status. A tiered diagnostic strategy, beginning with biochemical testing, supported by biopsy infrastructure, and progressing to genetic evaluation, can significantly improve CKD care equity. Policymakers and providers must work collaboratively to remove structural barriers, prioritize scalable innovations, and tailor interventions based on local health care maturity. Only through such coordinated efforts can we ensure timely, accurate diagnoses for all, irrespective of geography or socioeconomic status.

APPENDIX

List of Members of the ISN - Emerging Leaders Program Cohort 3

Mythri Shankar, Becky Mingyao Ma, Marek Kollar, Ana Catalina Alvarez-Elias, Carmen Elena Cervantes, Chimezie Godswill Okwuonu, Priti Meena, Rasha Hussein, Tae Won Yi, Yogeshni Chandra, Daniel Vincent O'Hara.

DISCLOSURE

All the authors declared no competing interests.

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Supplementary References.

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