RARE KIDNEY DISEASES (RKDs)



— THE SOLUTION -

Recommendations to Improve Outcomes for Individuals Living with RKDs and Their Families

1. EARLY DETECTION

- Strengthen early detection: Develop and implement case-finding approach, including genomic and newborn testing, to facilitate early diagnosis and intervention, particularly in high-risk and underserved populations (i.e. LMICs).
- Enhance diagnostic infrastructure: Invest in diagnostic tools and workforce training to reduce delays and improve accuracy in case-finding strategies.

2. RESEARCH AND INNOVATION

- Invest in etiological and risk factor research: Support studies to understand (rare) kidney disease causes and regional risk factors, informing targeted prevention and treatment strategies.
- Provide financial and technical support on development of new therapies: Encourage innovation in treatments and technologies, focusing on affordability and applicability in diverse healthcare settings (incl low-resource and underserved areas).

3. MANAGEMENT AND TREATMENT

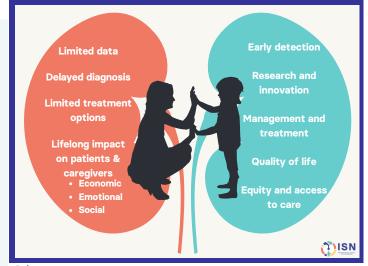
- Universal Health Coverage (UHC): Explicitly cover (rare) kidney disease diagnostics, treatments, and long-term care in UHC benefit packages to prevent financial hardship for patients.
- · Comprehensive integrated care models: Establish integrated care pathways involving multidisciplinary teams (nephrologists, surgeons, nutritionists, psychologists, primary care givers, etc.) to provide patient-centered management of (rare) kidney diseases.

4. QUALITY OF LIFE

- Socioeconomic determinants: Implement policies that mitigate the effects of (rare) kidney disease on education, employment, and mental health, including caregiver support.
- Psychosocial support: Ensure access to mental health and counseling services to support patients and families in coping with (rare) kidney disease challenges.

5. EQUITY IN ACCESS TO HEALTHCARE

- Reduce disparities: Implement policies that address gender, geographic, and socioeconomic inequities in (rare) kidney disease care, ensuring services reach marginalized and underserved communities.
- Data collection: Collect and analyze data by demographic factors to identify and address gaps in (rare) kidney disease care and outcomes.
- Enhance multisectoral partnerships: Encourage collaboration among government, academia, industry, and civil society to enhance kidney health and major risk factors awareness.



International Society of Nephrology. Manifesto. International Society of Nephrology, n.d., www.theisn.org/about-isn/mission-vision-values/manifesto/. Accessed 9 May 2025. World Health Organization. Rare Diseases: A Global Health Priority for Equity and Inclusion. EB156/CONF.2, World Health Organization, 2025,

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