A deep dive in the calls to action

03

Reduce the socio-economic burden on patients and their caregivers by strengthening care pathways and offering cohesive legal and financial support mechanisms.

Patients and caregivers need consistent psychosocial, financial, and workplace support to mitigate the profound daily, emotional, and economic impact of RKDs.

3.1 Integrate psychosocial support in multidisciplinary care, including patient navigation support in reference centres. Facilitate family counselling and peer support groups.

3.2 Ensure early recognition of disability status and facilitate workplace and school accommodations for patients undergoing dialysis and transplantation. Recognise caregiver status and improve access to financial support schemes for caregivers of paediatric patients.

3.3 Standardise transition protocols for paediatric-to-adult care including age-flexible transfer (18-21 years old), readiness assessments, transition-specific psychological support, and post-transfer follow up.

04

Ensure that health technology assessments (HTA) and reimbursement decisions for rare kidney diseases (RKDs) reflect the full clinical and patient experience.

HTA frameworks must recognise the disease specific evidence that is currently disregarded, including surrogate endpoints and quality of life aspects, to enable timely and equitable access to targeted therapeutic options.

4.1 Ensure recognition by HTA bodies and payers of registries data and disease-specific predictive markers, such as albuminuria, proteinuria and eGFR, that are used by EMA as indicators of clinical benefit and predictors for kidney survival.

4.2 Accelerate clinical guideline updates to reflect emerging evidence and patient quality of life aspects and thus enable earlier access to innovative therapies.

4.3 Mandate systematic collection of data on household financial burden and productivity loss (income loss, absenteeism, catastrophic health spending) associated with kidney disease and its treatments, including innovative medicines. Use these insights to inform policy adjustments at national level.