INTRODUCTION AND AIMS: Effective communication and shared decision-making improves quality of care and patient outcomes, but can be particularly challenging in pediatric chronic disease as children depend on their parents and clinicians to manage complex healthcare and developmental needs. We aimed to describe the perspectives of children with chronic kidney disease (CKD) and their parents with regard to communication and decision-making.

METHODS: Children with CKD (n=34) and parents (n=62) from six centers across six cities in Australia, Canada and the United States participated in 16 focus groups. Transcripts were analyzed thematically.

RESULTS: We identified four themes: (1) disempowered by knowledge imbalance (unprepared and ill-informed, suspicion of censorship, inadequacy as technicians); (2) recognizing own expertise (intuition and instinct unique to parental bond, emerging wisdom and confidence, identifying opportunities for control and inclusion, empowering participation in children); (3) striving to assert own priorities (negotiating broader life impacts, choosing to defer decisional burden, overprotected and overruled, struggling to voice own preferences); and (4) managing child’s involvement (respecting child’s expertise, attributing ‘risky’ behaviors to rebellion, protecting children from illness burden).

CONCLUSIONS: Parents value partnership with clinicians and consider long-term and quality of life implications of their child’s illness. Children with CKD want more involvement in treatment decision-making but are limited by vulnerability, fear, and uncertainty. There is a need to support the child to better enable them to become partners in decision-making and prepare them for adulthood. Collaborative and informed decision-making that addresses the priorities and concerns of both children and parents is needed.