



KIDNEY DISEASE: IMPROVING GLOBAL OUTCOMES
The Critical Input of Patient Voices in Guideline Development

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DISCLOSURES

- American Heart Association's CKM Patient Advisory Group
- National Committee for Quality Assurance's CKM Workgroup
- American Society of Nephrology's Saving Kidneys, Hearts, & Lives Learning Collaborative

WHY PATIENT VOICES MATTER

- Patients live the outcomes clinicians measure
- They experience the burden of treatment, not just the biology
- They reveal gaps invisible to clinical data
- They anchor guidelines in reality, not theory

KDIGO's COMMITMENT TO PATIENT PARTNERSHIP

- Patient representatives in workgroups
- Transparent methodology
- Global representation
- Lived experience as evidence

What Patients Bring That Data Cannot

- Context
- Culture
- Values
- Trade-offs
- Daily life constraints
- Emotional and spiritual realities

Lived Experience as Evidence

- Symptom burden
- Treatment fatigue
- Financial toxicity
- Care fragmentation
- Psychosocial impact
- Quality-of-life outcomes

How Patient Voices Strengthen Guidelines

- Improve clarity and usability
- Identify harmful or unrealistic recommendations
- Highlight inequities
- Ensure cultural and linguistic relevance
- Promote shared decision-making

Equity Requires Patient Partnership

- Marginalized communities face disproportionate burden
- Structural barriers shape outcomes
- Lived experience reveals hidden inequities
- Patient partners redesign recommendations for fairness

Case Example: CKD 2024 Guideline

- Patient input influenced:
- Communication strategies
- Risk-based follow-up
- Symptom assessment
- Shared decision-making
- Language around prognosis
- Patient-centered care planning

What Happens When Patients Are Missing

- Recommendations become unrealistic
- Burden increases
- Trust decreases
- Adherence drops
- Inequities widen
- Outcomes worsen

A Call to Action

- Patients must be:
- Invited to have an equitable seat at the table
- Heard
- Resourced
- Respected
- Integrated
- Not tokenized
- Valued

Closing Declaration

- When patients speak, guidelines gain wisdom.
- When patients lead, guidelines gain power.
- When patients partner, guidelines gain trust.

Thank You!

- For partnership
 - For courage
 - And for the gift of lived experience
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