

# Kidney Care Health Equity Framework

A collaborative report on deep conversations from stakeholders in the kidney community on addressing kidney health inequities

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*September 2024*

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Kidney Community  
Health Equity Summit  
Presented by U.S. Renal Care

## DISCLAIMER

The kidney community health equity summit was sponsored and led by U.S. Renal Care. Participation in the meetings and sharing experiences that contributed to the content of this report was voluntary. The suggestions contained in the report are the consensus of the workgroup. The authors, participants, or their affiliated organizations are not associated with liability that may arise in connection with the use of this report.

## TERMINOLOGY

Language used in this report is specific to the kidney community.

Kidney health equity refers to health equity specific to people living with kidney disease.

Additional terminology coined by the workgroup includes:

- Kidney Community Health Equity Workgroup (KCHE)
- Kidney Care Health Equity Framework
- Kidney Care Health Equity Model

## GRAPHICS AND TABLES

The kidney community health equity framework graphic illustrates domains the workgroup found relevant to addressing inequities in kidney care. The domain categories are key areas that contribute to addressing disparities in kidney care.

The suggested resource list contains links to services or additional information on resources that support domains in the framework and is not intended to represent all available resources in any domain.

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## EXECUTIVE SUMMARY

Kidney disease affects 1 in 7 adults in the United States (hhs.gov); however, individuals from diverse groups remain disproportionately affected, creating disparities in kidney health outcomes (USRDS, 2023). Despite advancements in kidney care models, these persistent disparities have reinvigorated health equity efforts in kidney disease. Requirements such as organizational commitments to health equity, including demonstration of that commitment through a health equity plan by the Centers for Medicare and Medicaid Services (CMS) and Centers for Medicare and Medicaid Services Innovation Center (CMMI), aim at addressing health equity in kidney care.

According to the Centers for Medicare and Medicaid Services, health equity is the attainment of the highest level of care for everyone, where everyone has a fair and just opportunity to attain their optimal health regardless of race, ethnicity, disability, sexual orientation, gender identity, socioeconomic status, preferred language, geography, or other factors (CMS.gov). Addressing health equity in kidney disease, therefore, must consider those characteristics stated in the definition of health equity, such as race, ethnicity, disability, sexual orientation, gender identity, socioeconomic status, preferred language, geography, and other factors that drive health disparities among certain groups including the complexity, burden, and challenges that are unique to kidney disease.

Uniquely positioned to lead conversations in addressing health equity in kidney disease are stakeholders in the kidney community who came together and formed the Kidney Community Health Equity (KCHE) workgroup. The workgroup focused on leveraging knowledge and expertise across a broad range of experiences to discuss challenges, experiences, and actionable solutions that address inequities in kidney disease. The workgroup's goal was to develop a *Kidney Care Health Equity Framework*. This framework considers the unique challenges of kidney disease from which kidney care health equity models that address disparities in kidney disease can be derived.

The workgroup met for nine months, discussing data, research, experiences, resources, challenges, and actions related to addressing health inequities and disparities in kidney disease. The following charter was established to guide discussions:

Project name: Kidney Community Health Equity Summit

- Acronym: KCHE
- Participation: Voluntary
- Workgroup: Two participants from each stakeholder organization
- Meeting cadence: monthly for 1 hour up to the meeting date of September 28, 2024.
- **Expectations:**
  - Bias-free approach
  - Collaboration
- **Outcome:** Develop a Kidney Care Health Equity Framework.

The workgroup intentionally focused on actions that impact disparities in kidney disease, utilizing the journey from risk assessment through early and late-stage kidney disease, treatment options, modalities, and end-of-life as pillars to guide discussions. At each stage, discussions took a deeper dive with probing questions, challenges, and actions that impact disparities. The emerging themes are domains of the Kidney Care Health Equity Framework.

## BACKGROUND

Health inequities in kidney disease are a major concern in healthcare today. These inequities refer to the disparities in the prevalence, diagnosis, treatment, and outcomes of kidney diseases among different populations. Factors such as race, ethnicity, socioeconomic status, geographic location, and access to healthcare contribute to these inequities. Individuals from minority and low-income groups are more likely to develop kidney disease and less likely to receive timely and appropriate treatment (National Kidney Foundation).

People with kidney disease live with challenges perpetuated by burdens that are unique to the stages and treatment options for kidney disease, and the impact of factors such as social determinants of health can compound these challenges. In 2021, the United States Renal Data System (USRDS) added a chapter to its report on health disparities, which included the impact of social determinants of health on disparities in individuals from diverse groups living with kidney disease.

With the plethora of data from institutions and organizations such as the USRDS, American Society of Nephrology (ASN), National Institutes of Health (NIH), The National Kidney Foundation (NKF), The American Kidney Fund (AKF), The Centers for Medicare and Medicaid Services (CMS) on health disparities in kidney disease, the KCHE workgroup acknowledged disparity data and began with describing what health equity meant from the perspective of various stakeholders in the workgroup. Some of the examples shared involved:

- Addressing persistent disparities in the kidney journey from risk assessment through end-stage kidney disease (ESKD) treatment choices and end of life.
- Addressing social determinants of health.
- Valuing an individual with kidney disease, therefore, means caring about the impact of disparities on the individual.

The cost of addressing socio-economic and structural determinants of health in kidney care emerged as a persistent challenge to addressing kidney health equity. The lived experiences that come with geographic factors, such as concerns for safety in certain neighborhoods where individuals with kidney disease reside, can limit access to modality choices such as home dialysis. Other examples of lived experiences, like the paradox of transportation availability, highlighted that even when transportation services are available, approved routes are often longer due to multiple stops, impacting the quality of life.

This workgroup's approach focused on actions that stakeholders such as organizations, providers, caregivers, and policymakers can take to address kidney health equity. Noteworthy is that these actions are not intended to represent all that can be done to address health equity; rather, they are a summary of suggestions from various stakeholders who agree these actions make a meaningful impact in addressing kidney health equity.

The workgroup intends to make this framework publicly available and suggests a health equity model comprised of action item(s) from all domains of the framework.

# KIDNEY CARE HEALTH EQUITY FRAMEWORK

The Kidney Care Health Equity framework consists of pillars and domains. Pillars include the kidney disease journey, starting with risk factors, chronic kidney disease, treatment options, end-stage kidney disease, and end-of-life. These pillars served as a guide for focused and deep conversations on actions that address kidney health equity.

The KCHE framework supports delivering care through a health equity lens. For these discussions, this means applying knowledge about the impact of social determinants of health in care delivery. Effective utilization of the framework includes incorporating action items from the framework's domains into a kidney care health equity model.

Additional considerations include:

- Monitoring tools to track actions.
- The domains of the framework are multidimensional and are not mutually exclusive.

Figure 1





Four themes emerged from the workgroup's discussions that formed the domains of the framework. These themes were:

## 1. Community Partnerships and Collaboration:

Community collaboration or a network of community organizations is critical to eliminating disparities, as healthcare providers cannot close kidney health disparity gaps alone. Collaboration with community resources and local leaders can expand trust or provide access to resources that impact disparities driven by social determinants of health. For example, access to the right diet at a local food kitchen to manage diabetes, access to safe school grounds, which can be utilized as a walking trail for exercise, or local leader support for initiatives that promote kidney health in their community.

The community partnership and collaboration domain emerged as a theme in addressing health disparities across the kidney disease spectrum. This domain focuses on community-centric partnerships that consider diverse characteristics, historical context, equitable access to resources, and collaborative efforts that make meaningful and measurable impacts.

Collaborative partnership actions at the community level can address immediate health needs and contribute to the long-term well-being of individuals by addressing some of the environmental and social factors that contribute to health disparities. Some actions discussed that address disparities specific to community partnership and collaboration include:

- Utilizing existing data to identify states and communities at high risk for chronic kidney disease.
- Collaboration with community-based organizations, kidney care organizations, and subject matter experts in local communities to offer consumable information on risk factors and behaviors that impact those risk factors.
- Approaching and navigating partnerships and collaborations with humility from kidney communities as learners to build and establish trust in local communities.
- Collaboration from the kidney community with trusted resources such as community faith-based organizations when introducing conversations on risk factors for kidney disease.
- Engaging with local community subject matter experts, for example, physicians, nurses, dieticians, or social workers, as trusted sources for educational opportunities.
- Compilation of a database by the local community of available resources that address the needs of the kidney community, such as:
  - Resources that support requirements for getting a patient on the transplant waitlist.
  - Access to various types of transportation
  - Food banks
  - Support groups or self-advocacy support.
- Accessibility considerations of individuals with disabilities, generational diversity, or technology preferences.

## 2. Cultural Competence:

Cultural competence plays a crucial role in addressing health equity in kidney care. It is the ability to integrate and transform knowledge about individuals and groups of people into policies, standards, practices, and attitudes that are specific and appropriate to cultural settings to increase the quality of service and produce better outcomes (cdc.gov).

Health literacy for the individual is the ability to seek, comprehend, and utilize health information and services to make informed decisions (nih.gov). In contrast, health numeracy focuses on the ability to access, utilize, interpret, manage demand, and communicate mathematic information and ideas during adult life (cdc.gov). Therefore, health literacy and numeracy should be discussed in the context of cultural competence and considered from the perspectives of the patient, family, caregiver, and provider.

Some examples of actions that address disparities related to health literacy and numeracy in kidney disease include:

- Cultural sensitivity in delivery method of patient education-
  - Listening to the patient's story to determine the best education approach.
  - Seeking preferred mode of delivery of education from the patient, for example, visual versus auditory.
  - Consider suggestions for approaching patients based on widely known cultural preferences in diverse groups.
  - Include patients' values, spirituality, community, family, and ethical values when planning care.
- Being thoughtful about which care team member delivers education to the patient, including consideration of the level of rapport and trust the team member has with the patient.
- Learn about the patient's preferences and cultural considerations and encourage the patient to advocate for themselves.

The domain of Cultural Competence captures the influence culture has on health, wellness, illness, death, and dying. Cultural competence in care delivery promotes meaningful experiences and trust between the individual and their healthcare provider (hhs.gov).

## 3. Education and Awareness:

Education about risk factors and kidney disease at the local community level must include the association of risk factors such as diabetes and high blood pressure with kidney disease. The domain of education and awareness captures the importance of self-awareness of caregivers or providers and organizational or institutional awareness of systems and processes, including resources available for education on actions that address health equity. Some considerations of how education can address health equity in kidney disease include and are not limited to the following:

- Coordinate with existing patient organizations such as diabetic associations and cardiovascular associations and establish a cadenced community-based education series as a vehicle to deliver ongoing education and resources regarding risk factors for kidney disease.
- Education at the local community level should include the association of risk factors with kidney disease.

- Partnership with local resources such as food kitchens, food banks, and food pantries to educate meal preparers on food choices and meal recipes harmful to persons with kidney disease and kidney disease friendly choices.
- Utilize social media to share kidney friendly recipes.
- During education, prioritize and be specific about what the patient must focus on, including the level of risk for kidney disease.
- A transplant navigator tool for patients and caregivers.
- A support person who can help patients navigate complexities associated with the transplant waitlist process, language barriers, and health literacy barriers.
- Address misinformation or biased information during patient education and disease management.
- Be mindful that the use of acronyms can be confusing to the patient.
- Develop education materials that are provider-agnostic for in-patient hospital programs that equip them to educate patients and ensure that the education continues in the outpatient clinic.
- Consider patient mentors and patients with similar experiences, such as cultural experiences or medical history experiences, to share success stories from mentors' experiences.

## 4. Holistic Care Coordination:

Care coordination includes the intentional organization of care activities and the sharing of information among all participants concerned with the individual's care for the purpose of achieving safe and effective care (ahrq.org). Holistic care coordination was discussed from the perspective of valuing the individual with kidney disease, considering the whole person, and including those factors such as psycho-socio-economic needs that impact the patient's ability to engage and participate in their care.

The domain of holistic care coordination captures a person-centric approach that considers the impact of social determinants of health on the individual with kidney disease. It also considers support systems and available resources that help address mental wellness and social determinants of health.

Some of the actions that can be addressed through holistic care coordination include:

- Assessments of social determinants of health needs for patients new to a dialysis clinic, incenter, or home modality.
- Community partnerships that support social determinants of health needs
- Addressing community safety through education and awareness of community members and local or state officials on how community safety impacts health.
- Including a screening question on availability, access, and types of technology in the health equity questionnaire. Knowledge of the kind of technology a patient has allows for equitable access to resources for the patient.
- Low-cost housing for patients that are disproportionately affected by kidney health inequities.
- Resources for a case management support person to help social workers navigate resources that address social determinants of health.
- State Medicaid programs that cover services for patients who are immigrants.

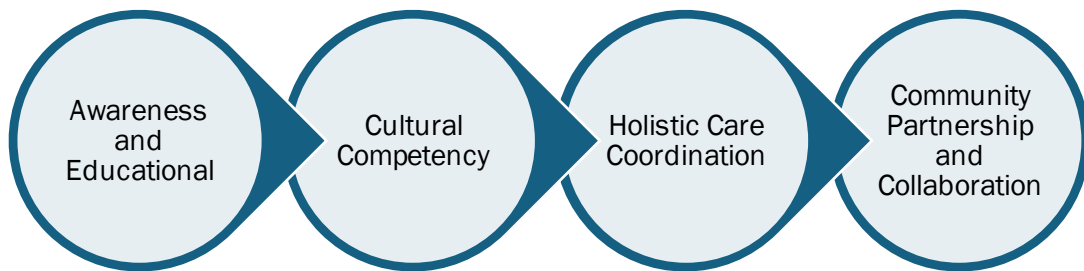
# KIDNEY CARE HEALTH EQUITY PLAN

## Outline:

- Statement of organization's definition of health equity and commitment to addressing health equity.
- Organizations health equity data and goals
- Health Equity governance and oversight process to operationalize plan.
- Tactical Health Equity Implementation Plan

Figure 2

### Health Equity Model



- Organizational assessment
  - Health equity data
  - Health equity goals
  - Practices/policies that address health equity goals
- Education for caregivers
  - Cultural competence and health equity
  - CLAS standards
- Assess and approach patient encounters and interactions through a Health Equity Lens
  - Awareness of the impact of SDoH
  - Referral process for identified socio-economic drivers of health
- Engage and partner with organizations in communities identified by health equity data.
  - Identify needs, goals, and actions for each community

## RECOMMENDATIONS

Achieving health equity in kidney care is an ongoing national health and moral imperative that requires persistence, resilience, and collaboration from stakeholders in the kidney community. The KCHE workgroup has begun work that must continue toward addressing health equity in kidney care. Reflecting on the nine months of collaborations that involved deep conversations and reflections about the impact of social determinants of health on the lived experiences of individuals disproportionately affected by kidney disease, it was clear that at any stage of the kidney disease journey, the influence of social determinants of health including other determinants of health such as financial, geographical, and cultural factors impact health equity in kidney disease. The following recommendations are suggestions from the workgroup:

### 1. **Structural level:**

- a. Policies that provide adequate resources to support a sustainable health equity model that addresses the hidden costs of coordinating and delivering person-centric holistic care.
- b. Policies that address known data on persistent disparities in kidney care

### 2. **Organizational level:**

- a. Systems and processes that promote the delivery of culturally competent care
- b. Advocacy for resources that support person-centric holistic care

### 3. **Community level:**

- a. Collaborative partnerships with chronic disease management organizations to deliver comprehensive education on risk factors and kidney disease.
- b. Collaboration with community leaders to address mistrust in the healthcare system

### 4. **Individual level:**

- a. Provider or caregiver
  - Integrate cultural competence in patient encounters and care delivery.
  - Integrate knowledge about social determinants of health in care delivery.
- b. Patient
  - Self-advocacy and civic engagement to address social determinants of health

# LIST OF FIGURES

Figure 1 – Kidney Care Health Equity (KCHE) framework

Figure 2 – Kidney care health equity model that incorporates the domains of the KCHE framework

## Suggested Resource list

Resource	Community Partnerships and Collaboration	Cultural Competence	Training and Education	Holistic Care Coordination
<b>Risk Factors and Kidney Disease</b>				
<a href="#">ADA - Education on Diabetes and Chronic Kidney Disease</a>	X		X	
<a href="#">NIH - Diabetic Kidney Disease</a>	X			
<a href="#">NIH - Eating Right for Chronic Kidney Disease</a>	X			X
<a href="#">CDC - Diabetes and Kidney Disease: What to Eat?</a>	-			X
<a href="#">CDC – High Blood Pressure</a>			X	X
<a href="#">CDC – Kidney Disease</a>			X	X
<a href="#">ADA - Embracing a Diabetes and Kidney-Friendly Meal Plan</a>	X		X	X
<b>Community Partners</b>				
<a href="#">NKF - Kidney Disease Prevention</a>	X			
<a href="#">AKF - Kidney Health Coach</a>	X		X	X
<a href="#">CDC - About the CKD Initiative</a>	X		X	X
<a href="#">Library Finder - Find your nearest library</a>	X			
<a href="#">USA.gov - Find local public libraries</a>	X			
<a href="#">HRSA - Find a health center</a>	X			
<a href="#">HHS - Think cultural health</a>		X	X	X
<a href="#">CDC- Culture and Language</a>		X	X	X
<a href="#">ESRD NCC - Hosting Kidney-Friendly Food Drives Toolkit</a>	X		X	X
<b>Food Banks and Food Kitchens</b>				
<a href="#">Feeding America - Find Your Local Food Bank</a>	X			
<a href="#">Food Pantries - Find food pantries</a>	X			
<a href="#">ESRD NCC - The Kidney Hub</a>	X		X	X
<b>Social Determinants of Health</b>				
<a href="#">211 - Information and resource line</a>				X
<a href="#">Find Help - Find free or reduced-cost resources like food, housing, financial assistance, health care, and more.</a>				X
<a href="#">Find Help - Neighborhood Resource</a>				X

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