



National Institute of
Diabetes and Digestive
and Kidney Diseases

Kidney Interagency Coordinating Committee *Ad Hoc* Meeting

Modifying the National Health and Nutrition Examination Survey Question on Assessing Kidney Disease Awareness

Virtual Meeting
May 16, 2022

Final Meeting Summary

Welcome and Meeting Purpose

Robert Star, M.D., Director, Division of Kidney, Urologic, and Hematologic Diseases (KUH), National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institutes of Health (NIH)
Jenna Norton, Ph.D., M.P.H., Program Director, NIDDK, NIH

Dr. Jenna Norton welcomed members and attendees to the NIDDK Kidney Interagency Coordinating Committee (KICC) *ad hoc* meeting and invited Dr. Robert Star to provide opening remarks and explain the purpose of the meeting.

Dr. Star also welcomed everyone and noted that the purpose of this *ad hoc* meeting was to discuss how the field assesses the awareness of kidney disease. He first provided an overview of this committee. The KICC was mandated by Congress in 1987 to meet yearly to encourage cooperation, communication, and collaboration among all federal agencies engaged in kidney research and related activities. Congress recognized the need for better coordination of the federal response to chronic kidney disease (CKD). Because of the enthusiasm, the structure changed from a *pro forma* meeting to one that meets twice yearly with the goal of coordinating a federal response to CKD. Dr. Star expressed appreciation to Dr. Andrew Narva, then-KICC Executive Secretary, for this transformation of the KICC meetings. The KICC has engaged in discussion and provided feedback on plans and ideas to make a noticeable change in kidney disease in patients. The NIDDK hosts the [Federal CKD Matrix](#), an online resource that summarizes CKD-related activities across federal agencies.

Because assessing kidney awareness is central to other NIH Institutes and Centers and federal agencies and organizations beyond those leading the multifaceted response to CKD, the NIDDK invited additional representatives to attend this meeting. These include representatives from the National Institute on Minority Health and Health Disparities, NIH Office of Disease Prevention, American Association of Kidney Patients, Renal Physicians Association, and NephCure Kidney International. Also in attendance were the invited speakers, Drs. Chi Chu and Delphine Tuot, as well as kidney disease expert Dr. Neil Powe, all of whom are leading researchers on this topic.

Dr. Star detailed the challenge to be addressed at this meeting. Research has shown that the manner in which people are asked (i.e., language used) whether they have kidney disease matters and makes a difference. Since 1994, the National Center for Health Statistics (NCHS) National Health and Nutrition Examination Survey (NHANES) at the Centers for Disease Control and Prevention (CDC) has used the following question (also known as KIQ.022):

- Have you ever been told by a doctor or health care provider that you have “weak or failing kidneys” (excluding kidney stones, bladder infections, or incontinence)?

Dr. Star emphasized that the renal community has realized that this question has not worked well and is challenging for clinicians and patients. In fact, ongoing studies suggest that this question is not very sensitive (i.e., results in low awareness) and underestimates awareness of CKD. The NIDDK is assigned ownership of the content of this NHANES kidney awareness question. A window of opportunity exists to modify this question to be included in the 2024 NHANES content. Dr. Star called attention to the September 12, 2014, KICC meeting, during which participants discussed the challenges with this CKD awareness question. He credits the early work of Drs. Powe and Tuot in showing options to improve the quality of this question. Through the continuous work of Drs. Tuot and Chu, the field now has more robust evidence to suggest a path forward. Before proceeding with the modification of KIQ.022, the NIDDK considers it essential to obtain input from the broader renal community.

Dr. Norton reviewed the agenda, which included a presentation on the research of the CKD awareness questions, the process for modifying the NHANES KIQ.022, and a general discussion. She noted that a meeting summary will be posted to the NIDDK website.

Performance of Questions to Assess Awareness of CKD

Chi Chu, M.D., M.A.S., Assistant Professor of Medicine, University of California, San Francisco (UCSF)
Delphine Tuot, M.D., Associate Professor of Medicine, UCSF

Dr. Chu explained that today’s presentation will focus on patient awareness of CKD as referring to patients’ knowledge of their individual CKD status. For example, a person with CKD knows that they have and is able to report that they have CKD. He provided an overview and summarized some of the published data.

Overview: CKD Awareness, NHANES Question, and Literature Review

A significant amount of the research in this area has been to study the NHANES assessment of CKD awareness defined as an affirmative answer to question KIQ.022, with the key words being “weak and failing kidneys.” Dr. Chu emphasized that early studies of CKD awareness using this question have documented low CKD awareness. In 2005, Coresh *et al.* and in 2008, Plantinga *et al.* reported that CKD awareness was generally less than 10 percent among U.S. adults (nationally representative sample) with CKD examined using NHANES data from 1988 to 1994, 1999 to 2000, and 1999 to 2004. In addition, only 50 percent of patients evaluated in these studies with stage 4 CKD were aware of their status.

In 2020, Dr. Chu and his colleagues conducted a comparison study of the awareness of other major chronic conditions—including diabetes mellitus (DM) and hypertension—that asked more direct NHANES assessment questions (e.g., has a health care provider ever told you that you have DM?). Results showed that in NHANES data from 1999 to 2016, even among patients who were at high risk for CKD (i.e., projected kidney failure risk of greater than 15% in 5 years) only 50 percent indicated awareness of “weak or failing kidneys” compared with 70 to 80 percent or higher awareness among patients with DM or hypertension.

Dr. Chu highlighted two main reasons for low CKD awareness as observed in the literature: (1) under-diagnosis or under-disclosure and (2) inconsistent terminology used with CKD. To better understand the landscape of CKD awareness studies and the questions used to ascertain this awareness, Drs. Chu, Powe, Tuot, and other colleagues conducted a systematic review of original research studies that examined this awareness. This review, which they published in 2021, used search criteria of CKD defined based on laboratory results (e.g., estimated glomerular filtration rate [eGFR] or urine albumin) and based on the exact wording of the question provided in the study. Thirty-two studies were included in the systematic

review. Of the 32 studies, 9 were from NHANES and 6 were from the National Kidney Foundation (NKF)–sponsored Kidney Early Evaluation Program (commonly called KEEP) study. In terms of the setting, 21 were general population studies, 4 were based in the primary care setting, 5 were based in a nephrology clinic, and 2 were inpatient studies. The questions for ascertaining CKD awareness asked about having kidney disease, weak or failing kidneys, or a kidney problem. Only a few studies examined CKD awareness using more than one question. The meta-analysis of pooled estimates showed an overall CKD awareness prevalence of 19.2 percent, with high heterogeneity and the highest estimate of 93 percent from studies in the nephrology clinic patient population. The lowest estimates were from studies of the general public, among which the overall CKD awareness estimates were 10 percent or less. Stratified by question wording used in two or more studies, “kidney problem” yielded the highest estimate for CKD awareness at 58 percent and “weak or failing kidneys” yielded the lowest at 12 percent.

Studies Comparing Questions for Ascertaining CKD Awareness

Dr. Tuot reviewed three studies: two cross-sectional investigations that have been published (the first of which was included in the aforementioned systematic review) and one usability evaluation that is in preparation. Under the mentorship of Dr. Powe at UCSF, Dr. Tuot examined the question: What are the sensitivities and specificities of different questions to ascertain CKD awareness in a primary care population? The patient population (a convenience sampling) consisted of 220 English-, Spanish-, or Cantonese-speaking adults who received primary care in a public health care delivery system and had either CKD or other chronic medical condition. Among those patients with CKD, one-third had early CKD (i.e., stage 1/2 CKD) and two-thirds had stage 3/4 CKD, with the majority having stage 3. The primary predictor—the CKD awareness question—mirrored the current NHANES question and included responses for four other single questions that included being told of having kidney disease, protein in the urine, a kidney problem, or damaged kidneys. The sensitivity and specificity of the questions were calculated, using laboratory results from the medical record as the gold standard. Data from the single questions were used to “estimate” the performance of combined or compound questions. The results revealed a sensitivity of 33 percent for the question on weak or failing kidneys and average awareness of 40 percent for the questions on a kidney problem and protein in the urine. An evaluation of the performance of the individual questions compared with the estimated performances of combined questions suggests that a combination question to ascertain CKD awareness may be of greatest value. For example, the best two-question combination—a kidney problem and protein in the urine—had a sensitivity of 53 percent, and this percentage was even higher with increased combinations.

In a second study of similar design, Dr. Tuot and colleagues investigated the sensitivities and specificities of the different questions to ascertain CKD awareness in the general population. The study participants consisted of the Healthy Aging in Neighborhoods of Diversity Across the Life Span (commonly called HANDLS) cohort based in Baltimore, MD. Fifty-eight percent—equating to 2,171 participants—of the HANDLS cohort with baseline and Wave 4 Protocol study visits were enrolled. The primary predictor included a compound question (not the NHANES question) used in the original HANDLS study asking about weak kidneys, failing kidneys, or kidney disease and the additional single questions described in the previous study. The sensitivity and specificity of the questions were calculated using laboratory results from the study as the gold standard. The results showed the highest sensitivity of 19.5 percent for the compound question. Dr. Tuot explained that similar results were observed in different subgroups of patients, including individuals of low socioeconomic status and health literacy and those with limited health literacy, defined by the Short Test of Functionality Health Literacy in Adults (s-TOFLA).

Last, Dr. Tuot and colleagues collaborated with the NKF to conduct a usability study to evaluate the language used to discuss kidney disease risk during clinical encounters, including during in-person and virtual office visits. This study used a think-aloud teaching exercise using the NKF online Kidney Score Platform designed to encourage individuals to learn about kidney disease and encourage discussions of

kidney disease between providers and patients. The study population consisted of 20 English-speaking veterans, 18 to 75 years of age, who had DM, hypertension, or CKD, and 19 clinicians involved in primary care delivery. Dr. Tuot highlighted two major themes that emerged from the study that are relevant to today's discussion: tension between lay and medical terminology when (1) discussing kidney disease and risk and (2) discussing kidney health tests, such as eGFR and urine albumin–creatinine ratio (uACR).

Conclusions and Recommendations

Dr. Chu presented the conclusions and recommendations. A critical need has been observed for consistent terminology for CKD aligned across clinical care, patient education, public awareness initiatives, and disease surveillance. The sensitivity of the “weak or failing kidneys” question is suboptimal to ascertain CKD awareness. The reasons are multifactorial and include inconsistency in the CKD nomenclature, varying language used by clinicians to describe kidney disease, and using medical terminology (e.g., CKD) without descriptors in laboratory reports. The recommendations are to consider a compound question to increase sensitivity without loss of specificity, include “protein in the urine” as a measure, and consider retaining the “weak or failing kidneys” language as a separate question to allow crosswalk (i.e., relationship mapping) between previous and future years. The proposed modified question is—

- Have you ever been told by a health care provider that you have a kidney problem, protein in the urine, or kidney disease (excluding kidney stones, bladder infections, or incontinence)?

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Processes and Proposal for Modifying Existing Question

Kevin Abbott, M.D., M.P.H., Program Director, NIDDK, NIH

Dr. Kevin Abbott explained the process to modify the NHANES KIQ.022. The NIDDK program official submits a letter of intent to NHANES to modify the question. NHANES reviews the request, and the changes would occur in the 2024 NHANES update. The NIDDK does not have the opportunity to add new questions for 2024. The proposed change must be submitted by May 23, 2022. Dr. Abbott, the

program official, has drafted and circulated the letter of intent to the NCHS, CDC, and colleagues in other organizations and can share it with the KICC, as well. He clarified that the proposed compound question can be submitted as a single replacement question. NIDDK's preference is a single question.

Discussion

- Dr. Powe commented that the studies examined CKD awareness across various subgroups and observed small improvements over successive NHANES years. He noted that in terms of demographics, awareness was higher among men, older individuals, and African Americans than their counterparts. Although it likely will require additional resources, Dr. Powe speculated on administering the current and proposed questions simultaneously to a small NHANES subsample to allow mapping to prior and future studies.
- Ms. Elise Hoover pointed out that some of the CKD community members have a rare kidney disease (e.g., polycystic kidney disease [PKD]), explaining that people who are connected with the PKD Foundation (PKDF) are much more aware of their own disease journey prior to a first visit. She called attention to a PKDF-sponsored study that included caregivers and family members responding to questions about PKD awareness and having been told about the need for dialysis or kidney transplant. This study showed that more people answered in the affirmative to the dialysis and transplant question than to acknowledging PKD awareness.
- Dr. Kristen Hood, who also works and communicates with a rare disease population that has CKD, explained that when people connect with NephCure Kidney International they already have an understanding that some underlying condition is occurring. For example, patients referred either have visited or been told to see a kidney doctor but do not understand the reason. It is common for those in the NephCure patient community to have been told they have a kidney problem and to return in 6 months to begin dialysis or get matched for a transplant.
- Dr. Narva commented that the proposed question would be an improvement and suggested that future research examine the issue of shame related to having CKD among the populations at the highest risk and with the greatest need to identify awareness. In his experience in treating patients with kidney disease, Dr. Narva has observed this issue being broader than self-denial and also suggested engaging social scientists in the research.
- Dr. Shamir Tuchman asked whether a loss in sensitivity occurs when asking the current NHANES question by specifying that a doctor or health care practitioner be the one to inform the patient. He also asked whether any other sources would have told the patient that they have a kidney issue or kidney problem. From his experience, Dr. Tuchman pointed out that patients diagnosed as children would not understand this information, which likely would have been discussed with their parents. Dr. Powe explained that someone might be alerted where a family history of CKD exists. Similar awareness studies have asked patients in dialysis units whether they had a first-degree relative who had kidney disease. Health screenings for blood pressure, DM, or cholesterol are another way to capture this information. Although patients could have ancillary care providers, a doctor in the health care setting primarily discusses this information with patients.
- Dr. Murray Sheldon observed that people who randomly see a doctor prior to being admitted to a hospital for treatment then receive the metabolic laboratory tests and panels, whereas people who routinely see a doctor and have elevated serum creatinine levels will automatically receive these tests. He asked whether there were ways to link intraoperatively an abnormal laboratory test that could notify both patients and their primary doctors of an issue or a change in the laboratory

measurement. Dr. Norton called attention to the electronic (e-) CKD phenotype developed by the NIDDK that is based on laboratory tests. She noted that setting an automatic mechanism to flag for CKD using this tool is possible as a way of capturing “likely” cases of CKD that have gone undiagnosed. However, the group who created the tool noted that it could be problematic to notify patients about this diagnosis for the first time via an automated alert—prior to their being notified by a health care professional. Since time is short and the NHANES question must be addressed today, she suggested considering this topic during a future KICC meeting.

- Dr. Paul Eggers expressed his support for the recommended change to the NHANES question, which is supported by well-documented research. He commented that the NCHS had not previously considered the addition of questions in NHANES for dialysis or transplant awareness because of the limited research and lack of necessary evidence.
- Dr. Tuot anticipates that questions about being told they need dialysis and/or a transplant likely would do well in individuals who have a rare kidney disease or advanced kidney disease, particularly patients with stage 4 CKD seen in the clinic setting. She expressed concern that such a question would have low sensitivity among individuals with early CKD, which is what constitutes the majority of this patient population. She suggested approaches to encourage high awareness among patients with early CKD that could be monitored over time, and then instituting more preventive measures. She added that some individuals do become aware of their kidney disease from laboratory results (e.g., eGFR) as opposed to being asked about weak or failing kidneys.
- Dr. Abbott observed a short-term task, which is the focus of today’s meeting, of changing the existing NHANES CKD awareness question, and a long-term task of adding new questions. Dr. Star asked if any individuals or groups represented disapproved of changing the NHANES CKD awareness question. Dr. Abigail Ryan expressed her support for the change and noted a broader issue: lack of communication to better understand why awareness among patients remains low. She emphasized that the types of communication (e.g., reading, mobile devices, videos) resonate differently across the generations. She suggested developing a series of formal short videos explaining protein in the urine and other CKD-related tests in a simple manner.
- Dr. Star asked whether the proposed question provides the necessary information to improve communication and noted that kidney disease is not well understood in the health care system as a whole. Dr. Narva reiterated that any changes to the existing question would be a significant improvement, emphasizing that this seemingly incremental step would be helpful to patients and clinicians. He also highlighted that kidney disease is complicated for clinicians, as well as patients.
- Dr. Meda E. Pavkov agreed with updating the question but is not convinced that the existing data will result in significant change. She suggested having both the current and proposed questions in operation for at least one NHANES cycle or conducting a feasibility study.
- Dr. Norton observed the common comment of having both questions operational in tandem to reset the baseline and suggested that although it might be beneficial to tracking long-term changes in awareness, given the general low sensitivity and specificity of the old question, using both questions might not be the best use of limited resources. Dr. Star recommended focusing on the proposed modified question, given the short time frame. He also commented that NHANES does not allow duplicate questions.

- Dr. Holly Kramer agreed with changing the question, but expressed concern that it does not reflect how providers are communicating kidney disease with their patients. She suggested ongoing research to address issues attributed to the less than optimal sensitivity, as well as studies on how providers in different clinical settings (e.g., primary care, nephrology clinics) are communicating kidney disease awareness.
- Dr. Eggers reiterated the current opportunity to change the CKD awareness question, but time is short to submit the information, noting that the purpose of this meeting is to achieve consensus on the change based on the current research.
- Mr. Richard Knight commented that the proposed question is an improvement and addresses an extremely important issue, given that the number of patients who initiate dialysis with a late diagnosis. This proposed change will ensure that the primary care physician asks the question or has a discussion with the patient. In terms of the level of difficulty, he agreed that kidney disease is a very difficult disease, but one that can be explained to patients. He continued that primary care physicians' communicating to patients that they have hypertension or protein in the urine does not tell them they have kidney issues. Regarding a patient's ability to understand, the terminology (e.g., protein in the urine) used can be unclear, even for individuals familiar with science.
- Dr. Susan Mendley observed the strong interest in improving the awareness of kidney disease across both patients and providers, which she noted that the renal community can do better at assessing. She added that more sophisticated educational tools about kidney disease are available in this community, but it is unclear whether they are actually being used well. Dr. Mendley suggested that this would be a valuable topic for the KICC to consider at a future meeting.

Determining the Path Forward

Dr. Star summarized that the NIDDK controls this CKD awareness question and is seeking input from the broader community about making changes. Research that was missing in 2014 is now available. The purpose of this meeting is to get consensus, which may not be 100 percent. He emphasized not concentrating on generating the perfect question, but forming one that accurately assesses how the NIDDK's educational programs are doing. Dr. Star reframed the question and asked whether any attendee thinks that the NIDDK should not change the existing question to this proposed question:

- Have you ever been told by a health care provider that you have a kidney problem, protein in the urine, or kidney disease (excluding kidney stones, bladder infections, or incontinence)?

Hearing no response, he asked for affirmative responses by raised hand, to which 47 attendees responded affirmatively.

Dr. Norton reminded the KICC that the NIDDK also has been discussing adding cystatin C to the NHANES laboratory testing. Dr. Star added that the NIDDK and CDC will share the expense of cystatin C testing in the NHANES sample subgroup. The availability of cystatin C values in NHANES will allow use of the better performing CKD–Epidemiology Collaboration creatinine plus cystatin C equation when assessing CKD using NHANES data.

Dr. Star welcomed ideas on what the federal government could do, in addition to its current initiatives, to address CKD.

- Dr. Kramer noted the need for education on uACR for providers and cardiologists, which the NKF has been addressing. She asked about a role for the NIDDK. Dr. Norton highlighted two

efforts in the NIDDK related to the uACR: the predictive approach of the e-CKD phenotype in making a diagnoses and the efforts of the NIDDK Laboratory Working Group to standardize urine albumin.

- Other attendees emphasized continuing to urge the U.S. Preventive Services Task Force to address CKD screening and exploring ways to better educate primary care providers, who tend to have competing time commitments.

Adjournment

Dr. Norton thanked the presenters and attendees for their participation. The next meeting is scheduled for September 16, 2022, and could be a hybrid of in-person and virtual attendance. KICC members and other attendees were requested to send any ideas for future meeting topics to Drs. Mendley and Norton. The meeting was adjourned.

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