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Ethical Considerations for Research in Chronic Kidney Disease of Unknown Etiology: Reflections from an Ethics Panel at the 4th International Workshop on CKDu

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Abstract:

Chronic kidney disease of unknown etiology (CKDu) is a form of tubulointerstitial kidney disease predominantly affecting impoverished agricultural communities in the global tropics, with major hotspots identified in Mesoamerica and South Asia. On February 14-16, 2024, the Consortium for the Epidemic of Nephropathy in Central America and Mexico (CENCAM) hosted the 4th International Workshop on CKDu in Antigua, Guatemala. The workshop hosted more than 100 experts from CKDu from Central America and around the world. For the first time, a panel discussion was dedicated to the ethical challenges of conducting CKDu research and interventions in low resource communities affected by the disease. Epidemiologists, nephrologists and scientists with expertise in community-based research and bioethics on the panel identified several key ethical considerations, primarily centered on researcher interactions with affected communities or other CKDu stakeholders. These included aligning research priorities, study designs, consent procedures, and the return of results with the needs and concerns of CKDu-affected communities; fostering equitable north-south collaboration in CKDu research; and ensuring that research findings are translated into meaningful actions to help mitigate the disease's impact, even as scientific understanding remains incomplete. The panel emphasized that affected communities, local healthcare systems, regional governments, and international researchers are all critical stakeholders in CKDu research. Ongoing discussion is essential to ensure that ethical considerations remain centered in response to emerging challenges and insights related to CKDu.

Abbreviations:

CKDu: chronic kidney disease of unknown cause
CKDnt: chronic kidney disease of nontraditional etiology
CINAC: Chronic Tubulointerstitial Nephritis in Agricultural Communities
CENCAM: Consortium for the Epidemic of Nephropathy in Central America and Mexico
CIOMS: Council for International Organizations of Medical Sciences
MeN: Mesoamerican Nephropathy
ICH: International Council on Harmonization
GCP: Good Clinical Practice

Introduction:

Since the first clinical case series was published in 2002, worldwide awareness of chronic kidney disease of unknown etiology (CKDu)-- a form of tubulointerstitial kidney disease occurring most often among young men laboring in agriculture and other strenuous occupations without traditional risk factors like hypertension or diabetes–has grown rapidly.[1] Significant occupational health and population-based research has been conducted in Central America, India, Sri Lanka, and other locations.[2,3] A rapid database search for CKDu, chronic kidney disease of nontraditional etiology (CKDnt), chronic tubulointerstitial nephritis in agricultural communities (CINAC) and Mesoamerican Nephropathy (MeN) yields more than 400 peer reviewed articles in the last decade.

Although the risk factors and exposures associated with CKDu continue to be mapped out and elaborated, individuals suffering from CKDu tend to be from more rural communities, lower socioeconomic status, and have limited access to healthcare.[4–7] These structural inequities present ethical challenges in biomedical research, yet discussion of these concerns remain limited in the literature. Key ethical issues include ensuring truly informed consent in populations with varying literacy levels, preventing research from exacerbating health disparities, and meaningfully returning results to participants. [8,9] Additionally, ethical research must promote equitable collaboration, ensuring local stakeholders shape study designs, and findings lead to community benefits rather than only academic advancement. This manuscript reports key findings from an ethics panel of international CKDu experts convened at a scientific conference, providing a framework for addressing ethical challenges in CKDu research and ensuring responsible engagement with vulnerable communities.

Methods:

Context:

The Consortium for the Epidemic of Nephropathy in Central America and Mexico (CENCAM) was founded in 2012 and unites researchers, clinicians, and key stakeholders to address the growing burden of CKDu. With a network of over 130 delegates from over 20 countries, CENCAM fosters global collaboration and knowledge sharing. CENCAM hosted the 4th International Workshop on CKDu from February 14th-16th, 2024, in La Antigua, Guatemala, to bring together global experts on CKDu from CENCAM, the Latin American Society of Nephrology (SLANH), and the Program in Work and Health in Central America (SALTRA) and discuss the current state of knowledge regarding the disease.

Panel composition

For the first time at the 2024 workshop organizers convened a moderated panel of experts to discuss ethical considerations for population-based, community- and workplace-based CKDu research. Experts were individually invited to participate in the ethics panel by the organizing committee based on their professional expertise and ongoing engagement with CKDu-affected communities. The panelists were purposefully selected from CKDu hotspot regions in Mesoamerica and South Asia to ensure geographic and contextual relevance. They brought a wide range of disciplinary expertise and institutional perspectives, including nephrology, epidemiology, public health, environmental health, and research ethics.

In advance of the workshop, organizers invited panelists communicated regularly by email and shared working documents to define the key ethics questions and shared responses they wished to provide during the live panel. The general membership of CENCAM was also invited to submit additional questions or topics which were also discussed in advance among the panelists. Panelists then each volunteered to provide detailed individual responses to questions during the live panel, which are provided in the Supplementary File.

Panel documentation

After the panel, working documents as well as individual panelists' scripts and notes and recordings were reviewed to provide a thematic analysis of the discussion. The synthesized summary was shared with all panelists for review, validation, and iterative refinement and resolution of points of disagreement.

Results:

The panelists emphasized the importance of established international research ethics guidelines, such as those outlined by the Council for International Organizations of Medical Sciences (CIOMS)[10] and the Good Clinical Practice (GCP),[11] as a foundational framework for ethical CKDu research. These guidelines provide essential principles for conducting research in vulnerable populations, ensuring respect for autonomy, beneficence, and justice. Additionally, the panel highlighted the need to adapt these guidelines to the specific challenges faced in CKDu-affected communities, including issues related to informed consent, community engagement, and equitable sharing of risks and benefits. A summary of key ethical considerations for interactions between CKDu researchers and affected patients or communities who may participate in research is presented in **Table 1**. These do not reflect a consensus but rather a summary of points made by panelists.

Table 1. Key elements related to engagement between researchers and communities affected by CKDu.

Topic	**Key Points**

Informed consent	- Work closely with the local Institutional Review Board (IRB) to ensure appropriate consent procedures.
	- Pay careful attention to language, both in translating to local dialects and presenting information at an appropriate education level which may encompass illiteracy.
	- Ensure adequate explanation of data and specimen storage procedures and protections as well as future use of these resources, particularly if they are to be made publicly accessible or stored in foreign institutions.
	- Ensure transparency and public accountability, especially regarding potential conflicts of interest
	- Address the lack of familiarity with advanced study modalities like genetic testing by appropriately describing these procedures in consent forms.
	- Build trust with communities and address existing mistrust stemming from past experiences of over-investigation and unmet needs.
	- Identify and avoid power dynamics that may lead to coercion which may exist in CKDu populations. Considerations particularly pertinent to CKDu research include:
	    - Therapeutic misconception that participating in research will provide medical care.
	    - Research in occupational settings may create the impression that participation is linked to ongoing employment.
	    - Excessive financial compensation may create undue influence in prospective participants who live in poverty.

Equitable benefit and sharing of risks	- Some populations in which CKDu was first identified have been extensively studied, to the degree that participation fatigue is a major issue; avoid overburdening certain populations with research participation requests. - Avoid potential exploitation of vulnerable populations via media and press, for example. - Information, interventions, and products developed through research should be developed with the researched population in mind, and accessible to these populations. - Participant privacy remains paramount. - Ongoing research into causality should not preclude acting upon risk factors, like occupational heat stress, that have already been established in certain populations affected by CKDu.

Honesty regarding scientific uncertainty	- Thoroughly consider how best to provide information about risks and benefits for fully informed consent when using advanced and exploratory analytical modalities, such as genomics and metabolomics. - Certain analyses may not be conducted immediately, and/or may in the future reveal clinically actionable findings. Careful planning to be able to act on these findings is essential. - When clinically actionable, results from advanced research should be shared with participants' healthcare providers for proper interpretation.

Return of results	- Participants must be clearly informed about which results will be returned, timelines for return of results, and how results may be interpreted.
	- Research findings that are publishable are likely also valuable to affected communities. Researchers should communicate these findings clearly and accessibly.
	- Clear and transparent protocols for returning individual-level results to participants are essential, including the return of clinically relevant incidental findings. (e.g., genetic results that have nothing to do with CKD)
	    - Results must be communicated in an accessible, culturally appropriate manner to ensure participants understand their implications.
	    - Researchers should ensure necessary funding is in place for ethical and timely return of results.
	    - Results should be paired with actionable information and delivered in a manner that allows for immediate discussion.
	    - Return of results from advanced modalities may require additional resources; for example, provision of genetic counseling when returning genetic findings.
	    - Coordination with participants' existing providers and healthcare systems is vital for achieving optimal health outcomes.

Translating research findings to action benefiting affected communities	- Researchers should find ways to support evidence-based CKDu policies, which may include both government and industry levels as well as programs demystifying and destigmatizing disease on a community level. - Researchers should work in partnership with communities to determine how best to report hazards identified back to participants and communities who are or may be exposed. - Research benefits must flow equitably to the communities bearing the burden of this disease. - The lack of a fully comprehensive understanding of CKDu - Researchers and stakeholders must be transparent about how research findings are being applied, who is responsible for taking action, and how the outcomes are monitored and

	evaluated. - Communities most affected by CKDu must have meaningful decision-making power in how research findings are applied.

Panelists emphasized that researchers have a fundamental ethical obligation to minimize risks and maximize benefits for participants in CKDu research, particularly in low-resource settings. This responsibility extends to ensuring informed consent, despite language and educational barriers. These barriers can be addressed through the translation of consent documents and collaboration with local ethics authorities. While not all panelists agreed with this statement, some proposed that it is ethically unacceptable to study populations at risk for CKDu who are exposed to known risk factors without simultaneously advocating for the removal of those risk factors. The example given was researchers studying occupational heat stress in CKDu must also advocate for protective measures against heat stress established in CKDu and in occupational health and safety standards.[12,13]

To the extent possible researchers must ensure that participants understand advanced study modalities, and that procedures for collecting, storing, and using biological materials and data are clearly explained and ethically overseen. Special consideration must be given to the ethics of kidney biopsies performed for research purposes only, particularly in areas with limited clinical access. In these cases, biopsy results and, where appropriate, interpretations should be shared with the patient's physician.

All panelists agreed that in communities with limited access to disease prevention and treatment, researchers must carefully consider referral pathways for identifying new cases and providing treatment. Protocols for returning results, including negative or incidental findings, must be in place, ensuring that participants are linked to appropriate healthcare services. Incidental findings, such as genetic findings unrelated to CKDu, require pre-planned strategies for reporting and counseling, respecting participants' rights to be informed while avoiding undue distress. Communicating these findings requires sensitivity to prevent panic or stigmatization, prioritizing actionable information.

Researchers have a responsibility to contribute to mitigation efforts, advocating for evidence-based policies and engaging in capacity building. To do so, researchers should actively search out partnerships with government, health care facilities, NGOs, industry, and community organizations. Key considerations related to collaborations with other stakeholders are outlined in **Table 2**. Again, these are not points of consensus but represent a summary of issues raised.

Table 2. Key elements related to engagement between CKDu stakeholders other than the communities affected by CKDu.

Stakeholders	**Key Points**
Researchers engaged in North-South collaboration	- Geography-independent equity between research collaborators is necessary throughout the research process, from conceptualization, to financial remuneration, to data use, publication, and intellectual property development. - Public accountability and transparency must be prioritized, especially around possible intellectual or financial conflicts of interest and future data use. - When specimens and data are stored outside the original

	setting, governance structures for future use of these specimens should have representation from the original setting, such as through inclusion of a local ethics committee or advisory board. - International researchers and sponsors should contribute to local capacity building for research and research oversight. - Ensuring that both North and South partners have access to adequate resources, including funding, equipment, and expertise - Recognizing the expertise and local knowledge that Southern partners bring to the table
Researchers and industries whose workers are affected by CKDu	- Researchers should fully consider worker-employer power dynamics of conducting research among workers at a work-site, with industry engagement (e.g., by not sharing individual participant results with the employer). - CKDu research conducted in conjunction with industry must also include commitments from industry to address the disease risk factors identified. - When industry funding is involved, research must maintain scientific integrity and independence and the funding source cannot influence analysis or the publication of findings. - Clear plans to translate occupational research findings into tangible benefits for the affected workforce are necessary. - Industries linked to CKDu should screen to prevent already sick workers from developing worsening disease. Individuals screened out should receive further assistance from the industry, although a number of questions on the specifics of this remain (Supplemental Methods).

Researchers and healthcare systems caring for CKDu patients	- Clear lines of communication and referral to healthcare providers must be established by researchers prior to beginning CKDu research.
	- Limited local healthcare capacity to care for CKDu patients should not deter identification of CKDu cases; efforts should be made to connect patients to regional or national care networks where local capacity does not exist.
	- Avoid implementing experimental treatments for CKDu patients without robust evidence of their efficacy and safety.
	- The unknowns of CKDu do not prevent healthcare systems from caring for these patients. CKDu patients may benefit from:
	  - Treatment of comorbid conditions.
	  - Counseling to avoid known risk factors for CKD.
	  - Counseling to avoid known risk factors for CKD progression in general, including nephrotoxic medications.
	  - Treatment of the sequelae of CKD, including anemia, hyperuricemia, and electrolyte imbalances.

Researchers and governments whose citizens are affected by CKDu	- Researchers should use their expertise to advocate for evidence-based healthcare policy and prioritization of CKDu care. - Researchers should engage with governments in capacity building for CKDu related public health and medical care infrastructure. - Researchers should report potential environmental hazards identified to appropriate government agencies.

Prioritizing effective solutions to mitigate risk factors is crucial, and panelists hope research in the future will shift from solely searching for a cause. The ethics of exploratory pharmaceutical clinical trials must be carefully considered, given the lack of clarity on CKDu's cause; at present there remains no clear therapeutic target for a trial. Collaboration with local clinicians and researchers is crucial for building trust and ensuring clear communication about research studies. Researchers should actively contribute to improving health outcomes by translating their findings into evidence-based recommendations that can be communicated with healthcare, industry, and government stakeholders. They should engage in local capacity building and work with local ethics committees.

Preventing research imperialism requires careful consideration of who defines the research agenda and who benefits from the knowledge generated. Building trust between international researchers and local researchers, participants and/or academic collaborators requires acknowledging the presence of justified mistrust, rooted in the history of both CKDu research and international biomedical research in general. Addressing power dynamics and potential exploitation of vulnerable populations necessitates a contextual approach, strong ethics committee oversight, and fair compensation (financial and intellectual) for both participants and collaborators. Research priorities cannot be defined solely by sponsors and international researchers, but must be developed in partnership with local stakeholders and affected communities.

Discussion:

This first-ever panel discussion on the ethics of research in CKDu-affected communities at CENCAM provided an important forum for addressing key ethical considerations in CKDu research. Presenters engaged in dynamic discussions covering topics that included building trust and fostering collaboration with rural agricultural communities, best practices in South-North research partnership and capacity building, the disclosure and return of results to participants, and strengthening local health systems. Panelists spanned the global South and North and included ethics committee members from CKDu-affected regions, physicians, public health workers, and academic researchers. Two key themes emerged from the panel discussion: ethical issues related to researcher-participant dynamics, and ethical concerns regarding researchers' relationship with other key CKDu stakeholders.

Ethical issues identified by this panel exist within an established field of international biomedical research ethics. Historical criticism of trials, such as those involving antiretroviral therapy in Africa in the 1990s, exposed severe inequities in the distribution of burdens and benefits, where trial participants were often not provided existing standards of care while enrolled.[14] Similar ethical concerns are relevant to CKDu research, where vulnerable populations may be exposed to high risks without sufficient protection or benefit. Within nephrology research, specific ethical considerations have been well-reviewed by Nichol et al.[15] International guidelines such as those established by CIOMS and GCP are important additional foundations on which to base ethical practice in CKDu research.[10,11] Research frameworks like community-based participatory research have been developed to address power imbalances and ensure that the equitable inclusion of affected communities in the research process.[16]

The panel also raised an important ethical tension regarding the role of researchers as advocates. In communities where research findings reveal potentially harmful exposures or structural vulnerabilities, panelists discussed whether there is an ethical obligation to move beyond data collection and engage in education, policy dialogue, or even direct interventions. While some argued for a more traditional view of researcher neutrality, others emphasized that in settings with limited public health infrastructure, researchers often become de facto advocates. The panel acknowledged that while advocacy can enhance the impact of research, it also raises questions about maintaining scientific objectivity and managing stakeholder expectations. This issue warrants further reflection and dialogue, particularly in research involving marginalized or high-risk populations.

The approach used here to facilitate this discussion has several limitations. First, although iterative discussion was used by panelists and organizers to achieve consensus and summarize themes, this was neither a formal qualitative research study nor a formal consensus-building procedure, e.g. Delphi methodology. Future structure research studies may help to further systematically capture the perspectives of affected communities and stakeholders. Another limitation is that panelists focused primarily on issues of shared priority, and future work exploring country-specific concerns are needed. Conversation was also relatively limited on matters of economic compensation for communities and research participants, ownership and access to intellectual property, and researcher vs. community time horizons. Finally, panelists were a diverse group of researchers, advocates and clinicians with ethics experience, but additional perspectives from patients and patient representatives are needed.

Conclusion

The ethics panel at the 4th International Workshop on CKDu was a unique opportunity to bring together a diverse group of experts to discuss important ethical themes related to CKDu research. This report encourages readers to use the information presented as a framework for conducting ethically responsible research on CKDu, particularly in vulnerable, low-resource communities. We also stress the value of fostering equitable North-South collaborations and ensuring that research findings are translated into tangible actions that directly benefit affected populations. By articulating key ethical considerations and promoting sustained dialogue among researchers, policymakers, and community stakeholders, we hope to support the development of shared best practices grounded in justice, transparency, and respect for the communities most impacted by CKDu.

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Supplementary Material:

1. Composition of ethics panel (PDF)
2. Transcript of ethics panel (PDF)
3. Supplementary references (PDF)

Supplementary information is available at KI Report's website

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