

# Third International Workshop on Chronic Kidney Diseases of uncertain/non-traditional etiology in Mesoamerica and other regions

March 20-22, 2018

San José, Costa Rica

## Ethics for CKDu research: Addressing the challenges

March 22 – 7:00AM-7:50AM

### Session lead

Dr. Jorge Villalobos Alpizar. Bioethicist. Collaborator in biomedical research at the company "Establishment Labs". Formerly responsible for Research Ethics, CENDEISSS.  
Supported by Carla Saenz, PAHO Bioethics adviser

### Purpose

The session aims at (a) raising awareness about the ethical challenges posed by research on CKDnT, (b) providing the participants with the relevant resources to guide the ethical conduct of research with human subjects, (c) discussing strategies that can be used to ensure the protection of participants in CKDnT research, and (d) strengthening the skills to conduct an ethical analysis.

### Overview

It is imperative to conduct research to better understand, prevent and address CKDnT. We have the moral duty to ensure that such research is conducted ethically. CKDnT research can be ethically challenging: It disproportionately impacts disadvantaged populations in remote areas, where access to needed health care tends to be limited and health systems lack the mechanisms to capture relevant population data. Moreover, CKDnT affects prominently agricultural communities that are often poor. Some of them are migrant workers. Affected persons tend to have limited health literacy and depend economically on the agricultural industry, which in some areas is the sole possible employer. The agricultural industry, which often funds CKDnT research through various mechanisms, has a vast interest at stake: The results of CKDnT research can have a substantive economic impact on the agricultural industry. Potential research participants are in an extremely vulnerable situation and, despite recent notable progress strengthening research ethics in the affected region, the mechanisms to protect research participants and ensure the ethical conduct of CKDnT research are still weak.

In this scenario and given the moral urgency to conduct robust CKDnT research, how can we ensure that research is ethical? In this active and dialogic session led by a bioethicist specialized on research ethics, participants will discuss the specific ethical challenges posed by CKDnT research, along with questions such as: What is morally owed to research participants? How should researchers respond to the several vulnerabilities or potential research participants? Are there limits to the duties of investigators? What type of risks does CKDnT research can pose to participants? How can those risks be minimized? How should those risks be weighed against the benefits that result from the study? What are the potential adverse outcomes that researchers should be particularly aware of in the context of CKDnT? What type of research must undergo ethics review processes? What is the scope of a committee's ethics review? How should conflict of interest be managed and bias be avoided? Strategies to address these challenges will be discussed in the light of the most updated and comprehensive *International Ethical Guidelines for Health-related Research Involving Human Participants* (CIOMS 2016).

### Useful resources:

- CIOMS Guidelines: <https://cioms.ch/wp-content/uploads/2017/01/WEB-CIOMS-EthicalGuidelines.pdf> (Spanish: <http://iris.paho.org/xmlui/bitstream/handle/123456789/34457/9789290360902-spa.pdf?sequence=5&isAllowed=y>)
- Research ethics casebook: [https://apps.who.int/iris/bitstream/handle/10665/44118/9789241547727\\_eng.pdf?sequence=4](https://apps.who.int/iris/bitstream/handle/10665/44118/9789241547727_eng.pdf?sequence=4) (Spanish: <https://www.paho.org/hq/dmdocuments/2015/Ethical-Case-investigacion-internacional-salud-Book-Spanish.pdf?ua=1>).
- CDC policy to distinguish research from non-research: <https://www.cdc.gov/od/science/integrity/docs/cdc-policy-distinguishing-public-health-research-nonresearch.pdf>
- WHO ethics guidelines for surveillance: <https://www.who.int/ethics/publications/public-health-surveillance/en/> (Spanish: <https://www.who.int/ethics/publications/public-health-surveillance/es/>)

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<http://iris.paho.org/xmlui/bitstream/handle/123456789/34499/9789275319840-spa.pdf?sequence=6>)

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