Lack of research on an endemic noncommunicable disease in Honduras: the case of Mesoamerican Nephropathy (MeN), a bioethical perspective.

Dr. Guímel Peralta, Dr. Tatiana CarozzoCentral American Technological University (UNITEC), Honduras

Vulnerable population: strenuous work in rural areas







Keogh SA, Leibler JH, Sennett Decker CM, et al. High prevalence of chronic kidney disease of unknown etiology among workers in the Mesoamerican Nephropathy Occupational Study. BMC Nephrol. 2022;23(1):238. doi: 10.1186/s12882-022-02861-0.

Equity and Justice

75

Studies about MeN in the last 5 years

42,800

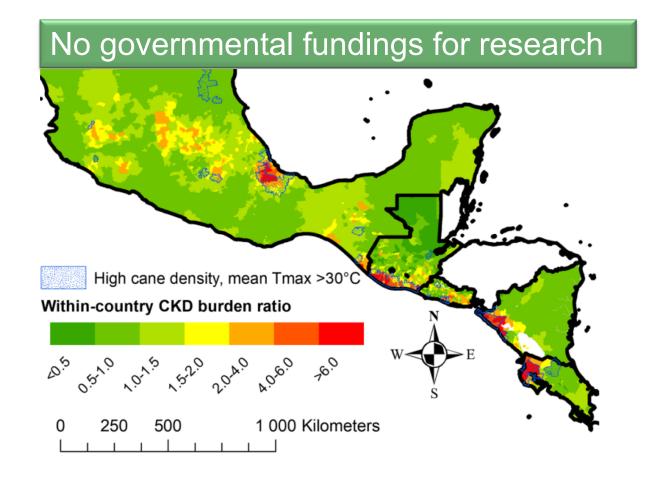
Studies about Alzheimer's disease in the last 5 years

Ethical Challenges





Ethical Challenges



Colonization of research

Chronic Kidney Diseases in Agricultural Communities Report from a Workshop

Susan R. Mendley¹, Adeera Levin² Ricardo Correa-Rotter Bonnie Joubert⁴, Elizabeth Whelan⁵, Brian Curwin⁵, Erik Koritzinsky⁴, Denise Gaughan¹, Paul L. Kimmel¹, Shuchi Anand⁶, Pedro Ordunez⁷, Ludovic Reveiz⁷, Diane S. Rohlman⁸, Carla Saenz⁷, Madeleine K. Scammell⁹, Robert O. Wright¹⁰, Robert A. Star¹

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⁵National Institute for Occupational Safety and Health, CDC (US)

⁶Stanford University School of Medicine

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⁹Boston University School of Public Health

¹⁰Mount Sinai School of Medicine

Keogh SA et al. High prevalence of chronic kidney disease of unknown etiology among workers in the Mesoamerican Nephropathy Occupational Study. BMC Nephrol. 2022;23(1):238.

Mendley, Susan R et al. Chronic kidney diseases in agricultural communities: report from a workshop. Kidney international. 2019;96(5): 1071-1076.

Criteria and Goals

Direct Benefits

- ✓ Early diagnosis
- ✓ Better treatment options
- ✓ Less mortality

Indirect Benefits

- ✓ Working force
- ✓ Reduce healthcare costs for dialysis
- ✓ Reduce economic burden on families

Why MeN is not a priority yet?

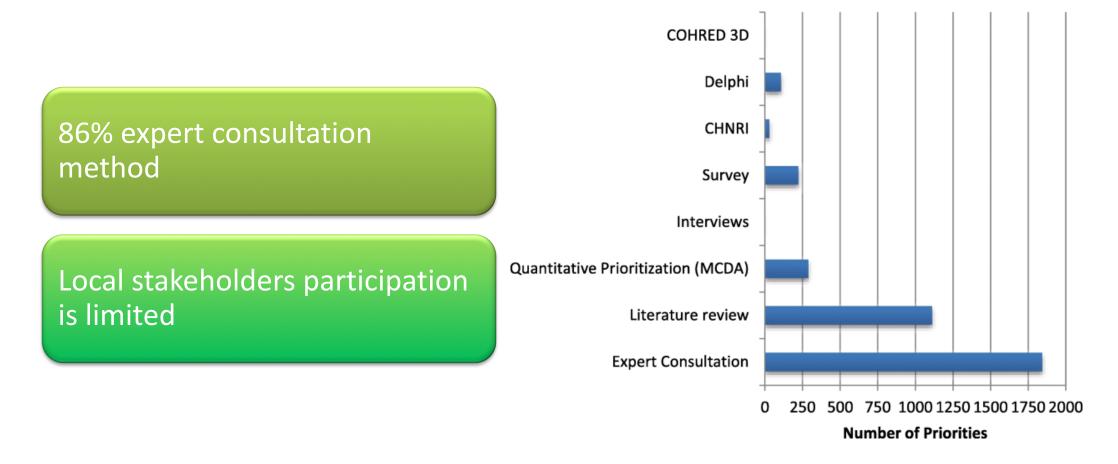
Government



Profitability



What about Non-governmental organizations?



Terry, R.F., Charles, E., Purdy, B. et al. An analysis of research priority-setting at the World Health Organization – how mapping to a standard template allows for comparison between research priority-setting approaches. Health Res Policy Sys. 2018: 16:116.

Global and Local

RESEARCH Open Access

High prevalence of chronic kidney disease of unknown etiology among workers in the Mesoamerican Nephropathy Occupational Study

Sinead A. Keogh¹, Jessica H. Leibler¹, Caryn M. Sennett Decker¹, Juan Jose Amador Velázquez ^{1,2}, Emmanuel R. Jarquin³, Damaris Lopez-Pilarte^{1,2}, Ramon Garcia-Trabanino^{3,4,5}, Iris S. Delgado^{1,2}, Zoe E. Petropoulos¹, David J. Friedman⁶, Magaly Rosario Amador Sánchez^{1,2}, Raul Guevara³, Michael D. McClean¹, Daniel R. Brooks² and Madeleine K. Scammell^{1*}

Only 2 countries

Only 3 local stakeholders

Why local participation is important?

Decolonization of funding

Priorities focused on future policies





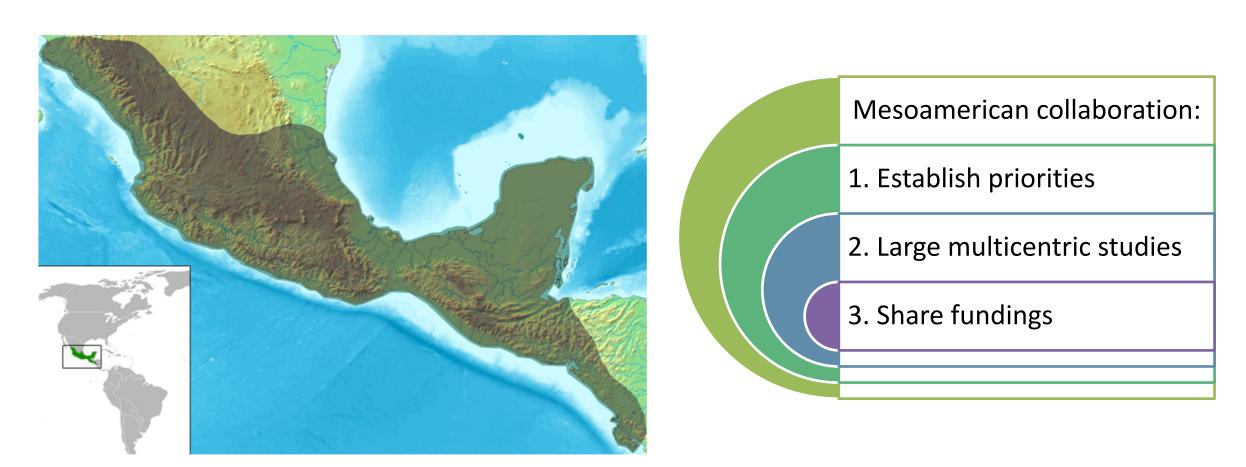
Education of local healthcare workers



Education of population



What do we recommend?



How to establish priorities?



International collaboration with more power to local stakeholders

James Lind Alliance method

Equity Lens



Aknowledgements

GFBR Planning Committee Adrienne Hunt