

## **Dr. Jose Luchsinger**

This proposal is an application for a Bioethics Research, Training, and Translation Supplement for the Northern Manhattan Center of Excellence in Minority Health and Health Disparities (NOCEMHD P60 MD-000206; PI. Luchsinger). NOCEMHD currently supports an administrative core, a research core, 2 clinical trials, a cohort study, and the Northern Manhattan Center of Excellence in Comparative Effectiveness Research to Eliminate Disparities (NOCERED; P60 MD000206-08S1). We have found several areas with unresolved bioethical issues in the conduct of our research activities in NOCEMHD and NOCERED. These issues are common to minority health research across CUMC. These specific issues are: Issue 1: The use of the clinical data warehouse (DCW) information to recruit minority individuals for clinical studies, including observational studies and clinical trials; Issue 2: Recruitment of minority individuals for studies or interventions that target relatives or families of persons with an index condition; Issue 3: Obtaining consent from minority individuals in clinical and research settings to have clinical and research information and biospecimens, including DNA, used for registries for future research studies. We propose to conduct a one year program led by Drs. Paul Appelbaum, a Bioethics expert, and Roberto Lewis-Fernandez, an expert in Bioethics and minority participation in research. Dr. Luchsinger, the NOCEMHD PI, will provide administrative, logistical, and scientific support for this initiative.

Our specific aims (SA) are:

SA1. To assemble a committee comprised of experts in ethics, bioinformatics, minority health research, members of the IRB, Office of HIPAA Compliance, and NYPH, to address the 3 particular bioethical issues, the use of the clinical data warehouse for minority health research, the identification of families and relatives, and obtaining consent from minority individuals to provide clinical data and biospecimens for open future research.

SA2. Convene focus groups of lay minority persons in the community and collect information on attitudes towards the 3 bioethical issues.

SA3. Conduct surveys of investigators and clinicians at CUMC, NYPH, and the community of Northern Manhattan about attitudes towards the 3 bioethical issues.

SA4. With the information gathered in SA1-3, a) conduct seminars in the last 6 months of the initiative, and b) prepare and disseminate publications of the findings.

The goal of this project is to create a harmonized legal, regulatory, and bioethical framework to guide the proposed bioethical issues.