

CGHE Summary of Current Activities as of February 2007

Partnerships

- a. Southcentral Foundation, Anchorage
 - Specimen bank project: community-based qualitative study to assess attitudes toward creation and use of specimen banks for research (Press, Burke)
 - Family history project: demonstration project to develop and disseminate education about family history to SCF employees (Burke)
 - Research education project: Creation of text and resources to educate community members about health research (Trinidad, Burke, Press)
- b. NWIC, Lummi Reservation
 - CBPR curriculum project: [see minority supplement application] Development of CBPR for NWIC and other tribal colleges (James, Starks, Burke, Freeman)
 - Community-based RA training (James)
- c. Other
 - SPIPA/Other: Pilot project to assess mammography utilization (James, Buchwald, Starks)
 - UW Indigenous Wellness Research Institute (Fryer-Edwards, James, Burke)
 - Center for Alaska Native Health Research (Burke, Fryer-Edwards)

Pharmacogenetics

- a. New pharmacogenetics projects related to warfarin and tamoxifen under development [subject of discussion] (Veenstra, Deverka, Garrison, Haga, Motulsky, Thummel, Burke, Carlson, Fujii, Lin)
- b. Special issue of Community Genetics on public health implications of pharmacogenomics (Veenstra, Burke)

Newborn screening

- a. Newborn screening policy analysis: review of policy documents 1960s-present (Crouch, Battuello, Watts, Burke)
- b. Medicaid budget impact of cystic fibrosis newborn screening (Watts, Wilfond, Burke, Ramsey, Riley)

Policy

- a. Translation framework paper: Recommendations for addressing the evidence gap for genetic tests (Deverka, Burke, Carlson, Edwards, Fryer-Edwards, Garrison, Haga, Kuszler, Press, Watts)
- b. Translational pathway analysis [see handout]: Develop the translational framework as a tool for describing the process of clinical integration and identifying policy concerns of particular relevance to medically underserved populations (indigenous populations in particular) (Kuszler, Anderson, Burke, Watts, Whitener)
- c. Other policy-related projects [see handout] (Kuszler, Watts)

CGHE Summary of Current Activities (continued)

Training

- a. Summer internship program with AI/AN recruitment (Marcus-Smith)
- b. PHG doctoral trainees (Barata, Laberge, Yu)
 - Laberge thesis: Chart review/key informant interview/ epidemiological assessment to evaluate physicians' utilization and perceived clinical utility of FVL testing
 - Yu thesis: investigation of the use of AIMs in genetic research
- c. Post-doctoral fellow (James)
 - Pilot project to evaluate barriers to mammography utilization
 - Development of CBPR curriculum and associated RA training & research [see minority supplement]
- d. Junior faculty fellow (Whitener)
 - Implications of NIH data-sharing policies: (1) survey to assess knowledge and beliefs of PIs; (2) legal analysis of different potential strategies for tribal control of data; (3) qualitative assessment of tribal member preferences of different approaches to data control

Testing Justice

Development of justice framework for evaluating implications of genomics for medically underserved populations (Fryer-Edwards, Goering, Holland, Fullerton)

New projects in planning stage

- a. Implications of genetics for disabilities care/disabilities rights, in collaboration with Treuman Katz Center for Pediatric Bioethics (Wilfond, Watts, Starks, Press, Miller, Fryer-Edwards)
- b. Community attitudes toward use of family history in health care (Edwards)
- c. Contribution of genetics to health disparities research (Fullerton)
- d. Implications of community based participatory research and relevant values for research ethics (Fryer-Edwards, James, Indigenous Wellness Research Institute, community partners)
- e. Health systems perspective on utility of genetic tests and technologies (Burke, Kuszler)