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Current Projects

Organizational Dynamics Affecting Clinical Research Participation through a Cancer Center
Pilot Proposal, under review by [NCTCTS!](#)

This research project seeks to identify social barriers within organizational structures that hinder patient participation in research by understanding: (1) how a person diagnosed with cancer becomes a clinical research subject at a cancer center, and (2) how organizational social behaviors might impact that referral and enrollment process. This anthropological analysis will systematically assess components of a university cancer center and affiliated referring sites through extensive participant-observation and interviews of clinical and administrative staff. Quantitative data from the clinical trial management database (Oncore) and the IRB protocol database will be analyzed to identify patterns in sub-optimal accrual to inform the sampling strategy of qualitative data collection and subsequent process of analysis.

Clinical and translational cancer research (CTCR) requires successful recruitment of diverse and clinically eligible patients into the full breadth of clinical and preventive trials. Yet, accrual to such trials remains a problem. Researchers will identify patterns in patient demographics, organ site, and referring sites that are associated with accrual to cancer trials. The study will conduct a comparative analysis of the organizational design and structures by which cancer patients enter trials and will analyze the "cultural environment" that might impact referral and enrollment processes.

This pilot will demonstrate the feasibility of anthropological research within a major biomedical research center. Findings will advance clinical translational science by revealing how institutional culture within and across organizational units may adversely impact patient participation in research thus extending the reach of CTCR to underserved populations.

Uncertain Futures: Logics of Lay Prediction in Cancer Screening

Article for special issue on Risk, Screening, and Surveillance in journal, *Health, Risk & Society*. A core logic of cancer control and prevention, like much in public health, turns on the notion of decision-making under conditions of uncertainty. Prediction of the likelihood of future states given current trends, deduced from the aggregation of relevant traits in a defined population. Standing at the other end of this continuum is the individual, perhaps a patient, and her healthcare provider, seeking to make sense of individual circumstances and the role of any given emergent technological "advance" in contributing to her personal well-being.

Decision-making depends on accessing and interpreting available clinical information, filtered through the lens of individual values and both cognitive and affective behavioral processes. Choices, that is, action, require patient and provider to relate abstractions to concrete current conditions of the self and life experience. With some cancers, the value of screening is confounded by the prospect of treatment and possible side-effects with significant impact on quality of life.

This paper is inspired by qualitative data from focus group analyses of the lay understanding of cancer risk to consider the conceptual significance of individual and population risk estimates, in the context of clinical uncertainty and ambiguity. I consider how individuals relate their own

possible future to a population's past performance. Comprehension of risk information is constrained by numeracy and probabilistic reasoning, but also impacted by notions of agency and social role. I juxtapose the clinical framework of medical decision-making against the lay meaning of cancer screening and preventive treatment in the life course of not-yet-patients. The paper examines the implication of such distinctions against the *realpolitik* of population health objectives: how do the ethics of prevention play out in the social process of cancer screening?

HPV Vaccine Knowledge & Acceptability: Adult Attitudes toward Universal Vaccination in 2006

A mixed-methods analysis of two internet omnibus surveys of US adults conducted prior to FDA approval and the release of ACIP recommendations and post-approval/recommendation. Surveys assessed men and women's awareness of HPV, the vaccine, and acceptance of a vaccine being administered to all pre-teen girls aged 10-13 by a physician. Produced in tandem, our study examines quantitative data analyses led by Dr. Jasmin Tiro ([Division of Behavioral and Communications Sciences](#)) and qualitative analysis of the open-ended data responses to the question, "Do you think it should be given to all pre-teen girls aged 10-13 by their doctor? [why or why not]" led by Dr. Lee.

Narratives for Translation: Framing Science as Salvation

For "[Cancer Stories: The impact of narrative on modern malady](#)" Medical Humanities Symposium marking the dedication of the [Indiana U Simon Cancer Center](#) at IUPUI and subsequent edited volume.

Narratives about cancer not only shape individual responses but collective action and reaction to the "dread disease." Until recently, the lion's share of scientific research has focused on basic biological mechanisms (tumor initiation, angiogenesis, apoptosis, invasion, metastasis), that is basic research often many steps before clinical application or public adoption. But it is the power of personal experience -- often patient anecdote -- that forms the social narrative of cancer as a public health threat, at once a story of risk, of hope and salvation by medical discovery.

Drawing on four years of ethnographic research at the National Cancer Institute, this paper will consider the role of narrative in the representations of the cancer research enterprise by the biomedical science (federal-industrial) complex. Cancer stories matter because they give a face to distant, often erudite laboratory practice, complex cellular, even social, processes. They humanize and re-frame both basic science and the scientist as vital actors in the drama of priorities competing for public legitimacy and support. The paper considers these stories within the emerging federal emphasis on "translational science" and the ethical underpinnings of accelerating scientific discovery from "bench to bedside, from bench to trench." The analyses will track both informal daily practice as well as formal on-the-record comments from public meetings on scientific agenda setting as well as organizational governance, against the backdrop of organizational development activities, scientific writing, and funding policy documents. Together, such moments assert objective science as a humane, if exclusive, act of sociality within a larger cultural narrative of cancer.