

Proposed 2013 CBSSM Research Colloquium Agenda

8:15 Refreshments

C. Daniel Myers, PhD, Daniel B. Thiel, MA

8:45 Welcome

1:30 Whose sense of public good? Public engagement results from the Michigan BioTrust and ethical implications
Ann Mongoven, PhD, MPH

Session I Presentations: "Gender Justice"

9:00 PhotoVoice: Promoting individual wellbeing and improving disaster response policies in Japan and beyond
Mieko Yoshihama, PhD, ACSW, LMSW

1:50 Citizen recommendations for communication about biobank participation and consent: Considering source, message, channel, receiver, and timing
Andrea C. Sexton, BA

9:30 Representing torture of women in custody in the U.S.
Carol Jacobsen, MFA

2:10 Panel Session Q&A

10:00 Break

2:30 Break

10:15 **Bishop Lecture in Bioethics:**
Global Gender Justice: Violence against women; whose responsibility?
Ruth Macklin, PhD

Session 3 Presentations: "Health Communication"

11:45 Lunch

2:45 Comparing male and female BRCA mutation carriers' communication of their BRCA test results to family members
Monica Marvin, MS

Session 2 Panel Presentations: "Public Perspectives on Biobanks"

12:45 Do non-welfare interests play a role in willingness to donate to biobanks?
Michele C. Gornick, PhD

3:15 A Gift for All: Everyone has something to give - Approaching dialysis patients about donating their organs
Allyce Smith, MSW

1:10 Which research? Public engagement and opinions about the research use of biobank samples

3:45 Putting patient-physician communication in context: An empirical analysis of sequential organization and communication transitions during visits for new diagnoses of early stage prostate cancer.
Danielle Czarnecki, PhD Candidate

Presenter	Affiliation	Title	Abstract
<p>Mieko Yoshihama, Ph.D., ACSW, LMSW</p> <p>Co-authors: Yukiko Nakamura, Ochanomizu University Department of Interdisciplinary Gender Studies, Tokyo, Japan; Tomoko Yunomae, Women's Network for East Japan Disaster</p>	<p>Professor, School of Social Work, University of Michigan</p>	<p>PhotoVoice: Promoting Individual Wellbeing and Improving Disaster Response Policies in Japan and Beyond</p>	<p>Conducted in collaboration with local women's organizations, PhotoVoice Project is aimed at strengthening gender-informed disaster policies and response in Japan by engaging the very women affected by the disasters in the analyses of their own conditions and advocacy efforts. PhotoVoice, a method of participatory action research, involves participants taking photographs of their lives and communities, followed by a series of small-group discussions about their experiences while sharing their photographs (Wang & Burris, 1997).</p> <p>After the Great East Japan Disasters of March 11, 2011, a diverse group of women (N=35) in five localities in the most disaster-affected areas of northern Japan participated in PhotoVoice group discussions (4-7 sessions in each location). A significant minority of the participants have been assisting other disaster victims as part of their regular employment or through volunteer effort.</p> <p>The participants' photographs and narratives identified various ways in which Japanese sociocultural and structural factors affected women's vulnerabilities in and after disasters. Traumatic stress and compassion fatigue were prevalent, yet denial and suppression were common response. Facilitated group discussions served as a collective space for grieving the loss and rebuilding their lives. Through repeated group discussions, participants also questioned and identified limitations and failures of the current disaster policies as well as those concerning nuclear energy. Also evident were participants' increased interest and desire to speak out, similar to the processes of politicalization and conscientization/conscientização (Freire, 1970).</p> <p>Findings of the project elucidate how individuals respond to trauma, dislocation, and devastation; how individual experiences are influenced by sociocultural and structural forces; and how individuals make sense of disaster and structural inequity, and to formulate action to address them. Findings of the project also suggest that participatory action research such as PhotoVoice could promote participants' growth and wellbeing by providing space for collective reflections, rebuilding, and action.</p>

Presenter	Affiliation	Title	Abstract
<p>Carol Jacobsen, MFA</p>	<p>Professor, The University of Michigan Penny Stamps School of Art & Design, Women's Studies; Human Rights Director, Michigan Women's Justice & Clemency Project</p>	<p>Representing Torture of Women in Custody in the U.S.</p>	<p>Representing Torture of Women in Custody in the U.S. More than a decade ago, Amnesty International launched its first ever campaign on torture in the U.S. Working with human rights activists, including prisoners, attorneys, artists, and others, the ongoing campaign has focused on the four point chaining, rape, retaliation, medical neglect and other forms of abuse of women occurring in U.S. prisons. As a grassroots, feminist filmmaker working with Amnesty on this issue, in my role as Director of the Michigan Women's Justice & Clemency Project, and as an educator of visual art, women's studies and human rights, many questions arise about issues of state and individual power, gender, race, representation, exploitation, censorship and voice as we struggle to make torture a visible and public issue in order to ultimately end it. This presentation will include an excerpt from my film, <i>Segregation Unit</i>.</p> <p><i>Segregation Unit, 30 min., 2000</i> Carol Jacobsen, Director Narrated by Jamie Whitcomb following her release from prison, the film documents the torture she and many others have suffered (and continue to suffer) in Michigan prisons. The film includes footage shot by guards that was obtained through subpoenas and the Freedom of Information Act in connection with Whitcomb's successful lawsuit against the State. Co-sponsored by Amnesty International, <i>Segregation Unit</i> is a nonprofit film available free to activists.</p>

Presenter	Affiliation	Title	Abstract
<p data-bbox="92 136 388 168">Michele C. Gornick, PhD</p> <p data-bbox="92 207 388 305">Co-authors: Kerry Ryan, MA and Scott Kim, MD, PhD</p>	<p data-bbox="413 136 688 305">Post-doctoral fellow/PhD, VA Health Science, Research & Development /CBSM University of Michigan</p>	<p data-bbox="749 136 1081 233">Do non-welfare interests play a role in willingness to donate to biobanks?</p>	<p data-bbox="1106 136 1990 909">Ethical debate has focused on protecting donor welfare and privacy interests. Little attention has been given to individual donor concerns about the moral, societal, or religious implications of research using their donation. The current study explores the impact of non-welfare interests (NWI) on participants' willingness to donate de-identified tissue samples and medical records to biobanks through an experimental online survey (N=1276; 46.3% women; 19.6% racial minority). Participants were more likely to donate to biobanks for NWI topics commonly associated with 'science' and medical research (evolution and stem cell research) than unfamiliar uses of biosamples (commercialization/corporate profit and risk assessment by insurance companies). In addition, mode (single vs. multiple scenario) and timing (before vs. after blanket consent) of NWI disclosure affect individual's willingness to donate. Further, key subject characteristics influence participants' willingness to donate, even after controlling for NWI scenario assignment (Racial minorities: OR = 0.59, 98% CI 0.34, 0.99, Evangelical Christians: OR = 0.55, 98% CI 0.35, 0.89, Liberal political views: OR = 1.66, 98% CI 1.06, 2.60). These data suggest that NWI issues have complex dimensions that require careful elicitation and evaluation of people's opinions regarding them. Further, policy recommendations for biobank donation based only on welfare and privacy may neglect other interests that are highly valued by potential donors.</p>

Presenter	Affiliation	Title	Abstract
<p>C. Dan Myers & Dan Thiel</p> <p>Co-authors: Ann Mongoven, PhD, MPH; Jodyn Platt, MPH; Tevah Platt, MPH; Susan B. King; Sharon L. R. Kardia, PhD</p>	<p>Myers, C. Dan, Robert Wood Johnson Scholar in Health Policy Research, Department of Health Management and Policy, School of Public Health, University of Michigan</p> <p>Thiel, Dan, Assistant Director, Life Sciences and Society Program, School of Public Health, University of Michigan</p>	<p>Which Research? Public Engagement and Opinions about the Research Use of Biobank Samples</p>	<p>Do potential biobank donors approve of using biobank samples for research, and do they care what kinds of research is done on their samples? We explored this question in various public engagement forums related to the Michigan BioTrust for Health, a recently established state research biobank of de-identified leftover newborn screening bloodspots. Results suggest that that the type of public engagement affects participant responses about whether research using leftover bloodspots is appropriate, and what types of research are should be conducted. In more superficial kinds of engagement participants show nearly-unanimous support for research, support that does not vary greatly across different kinds of research. However, more intensive forms of engagement find somewhat greater skepticism about research, and support that varies according to what aspect of a study is emphasized—target population, disease in question, type of analysis (e.g., genetic or not). Furthermore, more intensive engagements facilitate deeper reflection on the inherently uncertain nature of biobank research applications. This uncertainty brings issues of governance and oversight to the foreground. While there are some areas of broad consensus, there is also widespread disagreement on what kinds of research should and should not be pursued. On a practical level, this variation suggests that singular sources on public opinion may not be adequate to judge public support for biobanking, and that research and policy communities should consider best practices for eliciting educated public opinion on acceptable research. On a more conceptual level, the variety of conceptions of appropriate research uses suggests that informed consent and community oversight processes should account for this pluralistic conception of the public good.</p>

Presenter	Affiliation	Title	Abstract
<p data-bbox="92 139 359 272">Ann Mongoven, PhD, MPH Michigan State University</p> <p data-bbox="92 318 296 380">Co-author: Meta Kreiner, MSc</p>	<p data-bbox="415 139 724 380">Assistant Professor , Center for Ethics and Humanities in the Life Sciences and Department of Pediatrics and Human Development, Michigan State University</p>	<p data-bbox="749 139 1081 310">Whose Sense of Public Good? Public Engagement Results from the Michigan BioTrust and Ethical Implications</p>	<p data-bbox="1106 139 1990 488">Can policy-makers assume a consensus on what constitutes “the public good” of a public health biobank? If not, what are the implications for biobank ethical policies? We explore these questions in relationship to public engagement on the Michigan BioTrust. The BioTrust is a recently established state research biobank of de-identified leftover newborn screening bloodspots. BioTrust guidelines require that any research using bloodspots be (a) health research and (b) in the public good. The biobank operates with an opt-out “blanket” presumed consent policy for bloodspots saved before 2010, and an opt-in blanket consent policy for bloodspots saved from 2010 onward.</p> <p data-bbox="1106 529 1990 951">Community engagement on this issue suggests pluralistic conceptions of what constitutes the public good among Michigan residents. While some types of research generate broad consensus; others generate significant disagreement. Risk/benefit assessments also vary according to both degree and kind, including: potential for scientific/medical advances, economic considerations, and individual or group risk/benefit from biobank participation. Because the bloodspots come from children, some focus on benefits/risks for children; others do not. These results suggest pluralistic conceptions of what constitutes “public good” are at play when citizens assess both if and when the state should use biobank samples for research, and also whether they should allow research on their own children’s bloodspots.</p> <p data-bbox="1106 992 1990 1377">The results also have implications regarding informed consent processes and community oversight for a bloodspot biobank. Lack of consensus on what research is “in the public good” adds empirical weight to ethical requirements that biobanks inform donors before using their bloodspots for research, make lay research descriptions available, include community oversight in biobank governance, and ensure an opt-out mechanism. They suggest the worthiness of considering “by-study” or “tiered” consent options while underscoring their practical challenges. Significantly, even blanket consent and community oversight processes can be improved by acknowledging lack of consensus on what constitutes the public good as a risk of participation.</p>

Presenter	Affiliation	Title	Abstract
<p data-bbox="92 136 365 164">Andrea C. Sexton, BA1</p> <p data-bbox="92 207 365 305">Co-authors: Ann Mongoven, PhD, MPH; Meta Kreiner, MSc</p>	<p data-bbox="413 136 724 342">Masters of Arts Student in Health and Risk Communication, College of Communication Arts and Sciences, Michigan State University</p>	<p data-bbox="749 136 1081 378">Citizen Recommendations for Communication about Biobank Participation and Consent: Considering Source, Message, Channel, Receiver, and Timing</p>	<p data-bbox="1106 136 1955 483">Source, message, channel, and receiver are fundamental factors in models of the communication process. Public and clinical health practitioners must consider these factors in order to design effective health communication. This paper a) reports citizen recommendations for a multi-faceted educational campaign on the Michigan Biotrust; b) analyzes these recommendations by source, message, channel, and receiver characteristics; and c) argues that integrating these recommendations with communication theory suggests both practical strategies for recommendation implementation and extensions of theoretical models of the communication process.</p> <p data-bbox="1106 527 1969 734">The Michigan BioTrust for health is a state research biobank containing bloodspots leftover after newborn bloodspot screening. In November of 2011, seven deliberative processes engaged a representative sample of Michigan citizens. Five sessions were conducted in-person, each in a different Michigan city. Two sessions were run as Facebook discussion groups.</p> <p data-bbox="1106 777 1988 984">The primary recommendation from these juries is a multi-faceted campaign to increase public awareness of the BioTrust and its consent processes. The deliberators propose specific suggestions about who should provide information, what content should be communicated, the mediums through which education should occur, and their impressions of citizen responses to current and recommended BioTrust communications.</p> <p data-bbox="1106 1027 1959 1266">In addition to identifying source, message, channel, and receiver characteristics, jury participants distinctly emphasize the importance of communication timing. They consider the effect of timing on receivers' motivation and ability to process information, investigate their options, and ask questions. They also suggest a relationship between timing of communication about the Biotrust and public attitude toward the BioTrust.</p> <p data-bbox="1106 1310 1990 1516">Exploring jury participants' suggestions for education about the BioTrust has implications for clinical interactions, health education curriculums, and mass media campaigns regarding informed consent for biobanks, as well as ethical solicitation of biobank participation. Additionally, emphasis on timing as a key factor in communication may warrant further consideration in theoretical models of the communication process.</p>

Presenter	Affiliation	Title	Abstract
<p>Monica Marvin, MS</p> <p>Co-authors: Heidi Dreyfuss, MS; Lindsay Dohany, MS; Kara Milliron, MS; Sofia Merajver, MD, PhD; Elena Stoffel, MD, MPH; Beverly Yashar, MS, PhD; and Dana Zakalik, MD</p>	<p>Associate Director of the Genetic Counseling Program; Genetic Counselor in the Cancer Genetics Clinic; Clinical Assistant Professor; University of Michigan, Department of Human Genetics and Internal Medicine</p>	<p>Comparing Male and Female BRCA Mutation Carriers' Communication of their BRCA Test Results to Family Members</p>	<p>Current national guidelines state that patients with positive BRCA results should be urged to notify at-risk relatives. Most research on communication of BRCA results is limited to communication by females and suggests that communication to males occurs less frequently.</p> <p>The objective of this exploratory study is to identify gender-related characteristics in communication of BRCA results to improve familial communication.</p> <p>677 individuals who received genetic counseling from three clinics in Michigan were invited to participate. Subjects completed a 34-item survey comprised of novel and previously published questions exploring whom they informed, information shared, method of communication, and factors impacting the decision to undergo testing and disclose results. Communication patterns were examined within the entire cohort and comparisons were made between males and females.</p> <p>Participants included 35 males and 202 females. Overall greater than 78% of parents shared their test results with at least one of their children with a greater percentage of fathers disclosing to their children than mothers. The disclosure was mostly done in-person and the information shared did not vary much between genders except a greater proportion of mothers with daughter(s) discussed the impact genetics can have on their daughter's medical management than fathers with their daughter(s). For both males and females, the top reasons for disclosing to children included: 1) wanting to inform them about their risk, 2) feeling the results will impact management, 3) wanting to encourage testing, and 4) having a close relationship.</p> <p>In genetic counseling, gender of a BRCA mutation carrier does not appear to greatly affect the frequency or method of communication of test results. Furthermore, we found that communication to male and female relatives occurred with a similar frequency. This suggests that current practice effectively enables comprehensive family communication.</p>

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<p>Allyce Smith, MSW</p> <p>Co-authors: Ann Andrews, MPH; Jerry Yee, MD; Holly Riley, MSW; Reonia Chapman; Ken Resnicow, PhD</p>	<p>Program Coordinator, National Kidney Foundation of Michigan</p>	<p>A Gift for All: Everyone Has Something to Give - Approaching Dialysis Patients about Donating their Organs</p>	<p>The organ donor waiting list continues to grow. Individuals with End Stage Renal Disease (ESRD) are not typically viewed, by themselves or their health care team, as potential donors after death. However, ESRD patients are eligible to donate and may obtain a sense of empowerment in knowing they can give, as well as receive. Others feel that asking ESRD patients to sign up on the Donor Registry is unethical. This study will evaluate the effectiveness of using peer mentor to inform dialysis patients about their ability to sign up on the Donor Registry, ultimately increasing their numbers on the Registry.</p> <p>Using a cluster randomized design, this controlled intervention study is conducted in collaboration with the National Kidney Foundation of Michigan (NKFM), the University of Michigan School of Public Health (UM SPH), Greenfield Health Systems (GHS), Henry Ford Health System, and Gift of Life Michigan. Twelve dialysis units will be randomized to an intervention or comparison group. Participants in the comparison units receive mailings about organ donation while patients in intervention units are assigned peer mentors and meet 7 times over a 4-month period. Peer mentors are individuals with ESRD who have adjusted positively to living with kidney disease and volunteer to lend support to others coping with kidney disease. Peer mentor-patient meetings cover coping with chronic illness and leaving a legacy through deceased organ donation. During the meetings, peer mentors utilize Motivational Interviewing, a person-centered method of guiding patient decision-making and strengthening motivation for change.</p> <p>The primary outcome is mail/internet registrations on the Donor Registry. Pre/post surveys will be used to evaluate change in organ donation knowledge and attitudes, self-reported donation status, hope for the future, and quality of life.</p> <p>To date, 150 Greenfield staff, 33 peer mentors, and over 280 patients have participated in 10 dialysis units.</p>

Presenter	Affiliation	Title	Abstract
<p>Danielle Czarnecki</p> <p>Co-authors: Stephen G. Henry, MD; Valerie Kahn, MPH; Wen-Ying Sylvia Chou, PhD, MPH; Angela Fagerlin, PhD; Peter A. Ubel, MD; David R. Rovner, MD, FACP; Margaret Holmes-Rovner, PhD</p>	<p>PhD Candidate, Department of Sociology, University of Michigan</p>	<p>Putting patient-physician communication in context: An empirical analysis of sequential organization and communication transitions during visits for new diagnoses of early stage prostate cancer.</p>	<p>Background: Patients and physicians typically schedule visits to discuss new diagnoses for which patients have multiple treatment options. How communication is organized during these visits is unknown.</p> <p>Objective: To investigate the organization of communication tasks and the transitions between these tasks during visits in which patients and physicians discuss diagnosis and treatment of early stage prostate cancer.</p> <p>Methods: We characterized the sequential organization of 40 visits in which patients received a new diagnosis of early stage prostate cancer. We used transcripts to identify communication tasks and develop a coding system to identify transitions between these tasks. We analyzed a) the organization of communication tasks during these visits and b) how patients and physicians communicate during transitions between tasks.</p> <p>Results: We identified five major communication tasks, which typically occurred in the following sequence: diagnosis delivery, risk classification, options talk, decision talk, and next steps. Visit organization was physician-driven. Patients resisted physicians' attempts to transition from a) options talk to decision talk and b) decision talk to next steps by requesting more information about options and clarification about the decision making process, respectively. Physicians showed resistance when patients attempted to discuss decisions before physicians finished discussing treatment options. The overall organization of communication reflected physicians' focus on delivering a thorough discussion of treatment options. Patient speech was relatively uncommon but increased towards the end of visits. Patients showed some uncertainty about the visit purpose and their role in the decision making process.</p> <p>Conclusions: In visits discussing new diagnoses of prostate cancer, the overall visit organization and communication during transitions reveal an emphasis on discussing treatment options. Physicians' focus on discussing options fulfills an important obligation for informed consent, but may not be responsive to patients' informational or emotional needs.</p>

