Message from the PIs

As days turn cooler, the Building Trust team is settling into its new locations and rhythms. Along with us, Drs. Butler, Fryer and Garza have all re-located to the School of Public Health at the University of Maryland, College Park. Thanks to terrific efforts of our staff, our co-investigators at the University of Pittsburgh, the staff in the Dean’s Office in School of Public Health at the University of Maryland, and the grants administration at the National Institute on Minority Health and Health Disparities (NIMHD), our grant was transferred to the University of Maryland in record time. We’re happy to say that our partnership with Alan Meisel and David Barnard, in the School of Law and the Center for Bioethics and Health Law at the University of Pittsburgh, enabled us to move our staff to a new and more spacious office. As PIs, we continue to provide the scientific leadership for the initiative and work daily with our staff in Pittsburgh.

We are very excited about the elevation of our NIH sponsor, NCMHD, to the National Institute on Minority Health and Health Disparities (http://www.nih.gov/news/health/sep2010/nimhd-27.htm). This is a great recognition of the leadership of Dr. John Ruffin and his staff, and the clear importance of our national goal of achieving health equity by 2020. Drs. Butler, Fryer and Garza attended the July reception in honor of the new institute. The passage of the Health Care and Education Reconciliation Act of 2010 (H.R. 4872) authorized transition of NCMHD to become the National Institute on Minority Health and Health Disparities, expanding its mission to “…plan, coordinate, review and evaluate all minority health and health disparities research activities conducted and supported by the NIH institutes and centers.”

Special congratulations to Dr. Susan Reverby, a member of our National Advisory Board, whose work on the US Public Health Service Sexually Transmitted Disease Inoculation Study (1946-1948) garnered national media attention in early October (http://web.wellesley.edu/web/detailview.psm/1rcFilePath=/content/departments/publicaffairs/news/100110susanreverby.xml). President Obama and Secretaries Clinton and Sebelius formally apologized to the President of Guatemala, where the studies took place in the 1940’s. Writing in JAMA, the NIH Director, Dr. Francis Collins, and co-authors state that “Unethical uses of humans as research subjects represent appalling chapters in the history of medicine. To ensure that effective protections against such abuses continue to evolve and improve, it is essential to continue to learn from historical examples. Sadly, a new example has recently come to light” (pg. 2063). We encourage you to read the full article. The federal investigation, led by CDC, was ready with public documents about the study after having completed a review stimulated by Dr. Reverby’s work. Additionally, it was sobering to learn that Dr. John Cutler, principal investigator of the Guatemala study, was a member of the faculty at the University of Pittsburgh Graduate School of Public Health. Dr. Reverby’s finding that researchers leading the study actually infected participants with syphilis, gonorrhea and other STDs is a tragic example of abuse of vulnerable people and is yet another reminder of the vital significance of the work in Building Trust Between Minorities and Researchers.

INSIDE THIS ISSUE: 1 MESSAGE FROM PIS 2 PROJECT AIMS 3 EVENTS/BIOETHICS IN THE NEWS 4 BUILDING TRUST MEDIA

Message from the PIs

As days turn cooler, the Building Trust team is settling into its new locations and rhythms. Along with us, Drs. Butler, Fryer and Garza have all re-located to the School of Public Health at the University of Maryland, College Park. Thanks to terrific efforts of our staff, our co-investigators at the University of Pittsburgh, the staff in the Dean’s Office in School of Public Health at the University of Maryland, and the grants administration at the National Institute on Minority Health and Health Disparities (NIMHD), our grant was transferred to the University of Maryland in record time. We’re happy to say that our partnership with Alan Meisel and David Barnard, in the School of Law and the Center for Bioethics and Health Law at the University of Pittsburgh, enabled us to move our staff to a new and more spacious office. As PIs, we continue to provide the scientific leadership for the initiative and work daily with our staff in Pittsburgh.

We are very excited about the elevation of our NIH sponsor, NCMHD, to the National Institute on Minority Health and Health Disparities (http://www.nih.gov/news/health/sep2010/nimhd-27.htm). This is a great recognition of the leadership of Dr. John Ruffin and his staff, and the clear importance of our national goal of achieving health equity by 2020. Drs. Butler, Fryer and Garza attended the July reception in honor of the new institute. The passage of the Health Care and Education Reconciliation Act of 2010 (H.R. 4872) authorized transition of NCMHD to become the National Institute on Minority Health and Health Disparities, expanding its mission to “…plan, coordinate, review and evaluate all minority health and health disparities research activities conducted and supported by the NIH institutes and centers.”

Special congratulations to Dr. Susan Reverby, a member of our National Advisory Board, whose work on the US Public Health Service Sexually Transmitted Disease Inoculation Study (1946-1948) garnered national media attention in early October (http://web.wellesley.edu/web/detailview.psm/1rcFilePath=/content/departments/publicaffairs/news/100110susanreverby.xml). President Obama and Secretaries Clinton and Sebelius formally apologized to the President of Guatemala, where the studies took place in the 1940’s. Writing in JAMA, the NIH Director, Dr. Francis Collins, and co-authors state that “Unethical uses of humans as research subjects represent appalling chapters in the history of medicine. To ensure that effective protections against such abuses continue to evolve and improve, it is essential to continue to learn from historical examples. Sadly, a new example has recently come to light” (pg. 2063). We encourage you to read the full article. The federal investigation, led by CDC, was ready with public documents about the study after having completed a review stimulated by Dr. Reverby’s work. Additionally, it was sobering to learn that Dr. John Cutler, principal investigator of the Guatemala study, was a member of the faculty at the University of Pittsburgh Graduate School of Public Health. Dr. Reverby’s finding that researchers leading the study actually infected participants with syphilis, gonorrhea and other STDs is a tragic example of abuse of vulnerable people and is yet another reminder of the vital significance of the work in Building Trust Between Minorities and Researchers.
Community Engagement & Research: What Researchers and IRB Members Have to Say

Our objective in this aim is to conduct an online survey with the research community in order to determine best practices in the recruitment and retention of underrepresented racial and ethnic populations in research. Our survey officially closed on August 31, 2010. We had an excellent response from the research community with 424 principal investigators, co-investigators, research staff, IRB members and IRB staff who completed the survey. Please accept our thanks and appreciation to each of you who took the time to participate in this first of its kind survey on the subject of race, recruitment and retention. Your input into these topics will provide insight into how researchers may increase minority participation in research with new emphasis on respect, openness and understanding between those in the scientific community and minority communities. We look forward to sharing the results through future publications, presentations at national meetings and curriculum materials that are in the process of being developed for those of us in the research enterprise and the racial and ethnic communities with which we work.

Best Practices in Community Engagement in Research: What Researchers Have to Say

The goal of this objective is to conduct in-depth telephone interviews with a sample of researchers engaged with minority communities to determine best practices for recruitment and engagement of minorities in research. The interviews have been going well. Our partner, ICF MACRO, has conducted 28 of the 30 interviews they were contracted to complete. We expect to finish data collection by late November. The study participants are a geographically diverse group, who conduct research across a broad range of topics yet linked by their common aim to engage racial and ethnic minority populations. We are thankful to these researchers who have given up their time to contribute to this important work. The results will be shared with the research community through presentations, publications and a curriculum designed to enhance researchers’ ability to engage minorities in research.

Knowledge and Attitudes Toward Research: A National Household Survey

ICF MACRO is also our contractor on this important objective. Since June, we have been conducting telephone surveys, in both English and Spanish, with a random sample of African American and Latino adults. The goal is to identify the level of knowledge of research, research terminology, informed consent procedures, human subjects’ protections, trust and willingness to participate in research. At press time, 2,409 respondents have completed the survey; our target sample size is 2,500 participants. The telephone survey will continue through November 2010. We believe this is an important study and look forward to sharing results with colleagues around the country.

Educating Minority Communities about Research: Designing an Educational Intervention

The Building Trust team has partnered with the Healthy Black Family Project (HBFP), a program of the Maryland Center for Health Equity, whose members are actively involved in pilot testing the Building Trust Community Curriculum. Building Trust is working with the HBFP health coaches and members to develop five module educational sessions on the risks and benefits of participating in health research and how to make an informed decision about participation. The community curriculum will also address the effects of past research abuses, and how to stay informed and empowered in a new era of health research and health equity. Our first two sessions with community representatives in mid-October yielded insightful comments and valuable feedback from our partners at the HBFP. The Building Trust team is looking forward to three more sessions with the community representatives this fall. We are also planning to pilot test with Latino community members through our CTSI partners before preparing the curriculum for packaging and dissemination.

Educating Researchers about Minority Communities: Building Skills for Community Engaged Research

On July 14, the Building Trust PIs presented a 90 minute webinar, Distrust, Race, and Research: Overcoming Barriers to Recruitment and Retention of Minority Populations through PRIM&R to an audience of approximately 600. We are also pleased to announce that we have finalized our module outcomes and objectives for the Building Trust Researcher Curriculum. This is in line with a key objective designed to enhance the capacity of investigators to engage minorities and their communities. Four key modules will focus on understanding factors associated with distrust, improving the effectiveness of informed consent, and using best practices to respectfully engage minorities in research. We are also currently in production on a second recruitment and informed consent role playing scenario, which we will use as a teaching tool. As a reminder, the Building Trust team will also be presenting at the Annual Meeting of the American Public Health Association in Denver and PRIM&R’s Advancing Ethical Research conference in San Diego.
**Bioethics in the News**

"U.S. Apologizes for Syphilis Experiment" by REUTERS, *The New York Times*, Friday, October 1, 2010

The United States apologized for an experiment conducted on Guatemalan prisoners, women and mental patients in the 1940's in which U.S. government researchers deliberately infected participants with syphilis. The goal of the trial was to test penicillin. Dr. John C. Culter, a Public Health Service physician who was also part of the Tuskegee Syphilis Study, conducted the study. Secretary of State Hilary Clinton and Health and Human Services Secretary Kathleen Sebelius issued a statement saying "The sexually transmitted disease inoculation study conducted from 1946-1948 in Guatemala was clearly unethical." Susan Reverby, professor of women's studies at Wellesley College and a Building Trust National Advisory Board member, found out about the experiment when she was doing research for a book on Tuskegee Syphilis Study. She said, "In total, 696 men and women were exposed to the disease and then offered penicillin. The studies went on until 1948 and the records suggest that despite intentions not everyone was probably cured."


The NCAA has instituted a new policy requiring all new students participating in Division I sports, regardless of race to be tested for the sickle cell trait. The testing is being viewed as a case study in both the benefits and risks of large-scale genetic testing. Proponents of the testing say "We're trying to protect the health and well-being of our student athletes," said Yvette Rooks, the University of Maryland's team physician, who served on the NCAA committee that recommended the policy. "This amounts to a massive genetic screening program, with tens of thousands being screened," said Troy Duster, a professor of sociology at New York University and a Building Trust National Advisory Board member who studies racial implications of science. "This could have an extraordinarily heavy impact on black athletes. You are going to be picking out these kids and saying, 'You are going to be scrutinized more closely than anyone else.' That's worrisome."

http://www.washingtonpost.com/wp-dyn/content/article/2010/09/19/AR2010091904417.html

---

**BUILDING TRUST EVENTS**

**Community Curriculum Pilot Tests**
October, 2010 – December, 2010
Pittsburgh, PA

**APHA 138th Annual Meeting & Expo: Social Justice**
November 9, 2010
Denver, CO

*Building Trust between Minorities and Researchers* panel session with the APHA Ethics special interest group (session #4359.0)
Session description: http://apha.conference.com/apha/138am/web-program/Session30866.html
APHA annual meeting information: http://www.apha.org/meetings/

**Public Responsibility In Medicine & Research (PRIM&R)**
**Advancing Ethical Research Conference**
December 5-8, 2010
San Diego, CA

Conference information: http://www.primr.org/Conferences.aspx?id=7717

**Building Trust Webinars (presented in partnership with PRIM&R)**
March 2, 2011
*Putting Ourselves under the Microscope: Researchers Examine their Experiences with Engaging Minority Communities*
This webinar will highlight findings from qualitative interviews with researchers and results from an online survey with researchers, research staff and IRB members/staff.

June 14, 2011
*No More Excuses: Building Trust and Capacity through the Bioethics Research Infrastructure*
This webinar will introduce two curriculum products, one aimed at minority communities and one at researchers.

---

**Bioethics in the News**

"U.S. Apologizes for Syphilis Experiment" by REUTERS, *The New York Times*, Friday, October 1, 2010

The United States apologized for an experiment conducted on Guatemalan prisoners, women and mental patients in the 1940's in which U.S. government researchers deliberately infected participants with syphilis. The goal of the trial was to test penicillin. Dr. John C. Culter, a Public Health Service physician who was also part of the Tuskegee Syphilis Study, conducted the study. Secretary of State Hilary Clinton and Health and Human Services Secretary Kathleen Sebelius issued a statement saying "The sexually transmitted disease inoculation study conducted from 1946-1948 in Guatemala was clearly unethical." Susan Reverby, professor of women's studies at Wellesley College and a Building Trust National Advisory Board member, found out about the experiment when she was doing research for a book on Tuskegee Syphilis Study. She said, "In total, 696 men and women were exposed to the disease and then offered penicillin. The studies went on until 1948 and the records suggest that despite intentions not everyone was probably cured."


The NCAA has instituted a new policy requiring all new students participating in Division I sports, regardless of race to be tested for the sickle cell trait. The testing is being viewed as a case study in both the benefits and risks of large-scale genetic testing. Proponents of the testing say "We're trying to protect the health and well-being of our student athletes," said Yvette Rooks, the University of Maryland's team physician, who served on the NCAA committee that recommended the policy. "This amounts to a massive genetic screening program, with tens of thousands being screened," said Troy Duster, a professor of sociology at New York University and a Building Trust National Advisory Board member who studies racial implications of science. "This could have an extraordinarily heavy impact on black athletes. You are going to be picking out these kids and saying, 'You are going to be scrutinized more closely than anyone else.' That's worrisome."

http://www.washingtonpost.com/wp-dyn/content/article/2010/09/19/AR2010091904417.html
The Building Trust team and NBC WPXI-TV released the first special in a two part series of television programs as part of our community outreach efforts on July 24. Approximately 7,000 households tuned in for the initial broadcast of *Medical Research, Bioethics, and Race: Where Do We Go From Here* The special was repeated several times on WPXI-TV’s cable affiliates PCNC and RTV. On July 20, we celebrated with a special premiere at NBC WPXI-TV studios, which received coverage in the *Pittsburgh Post-Gazette* and the *Pittsburgh Tribune-Review*.

The second television special, *Building Trust Between Minorities and Researchers*, aired on NBC WPXI-TV on October 25. This program featured footage from a Town Hall meeting taped at WPXI studios with an audience of community members as well as researchers from the University of Pittsburgh. The special was moderated by David Johnson and Darieth Chisolm, news anchors at WPXI, as well as Drs. Quinn and Thomas, PIs of the Building Trust project. An additional panel included Building Trust Co-Investigators Drs. Fryer, Garza, and Butler. The Building Trust Investigators involved HBFP participants and other local community members in a discussion on moving beyond the barrier of mistrust and how we can work together to strengthen community involvement in research that aims to achieve health equity. The special also repeated several times on PCNC.

In addition to the television specials, Building Trust and NBC WPXI-TV created a public service announcement (PSA) featuring former Pittsburgh Steelers running back Jerome Bettis. The PSA is currently playing on WPXI and wpxi.com. NBC WPXI-TV will soon release a third PSA featuring Adrienne Trowery, a local African American woman, discussing her experience in a University of Pittsburgh research study. Several of the completed PSAs are currently available for viewing on the Building Trust YouTube Channel: [http://www.youtube.com/watch?v=_hwb0-F1yKs](http://www.youtube.com/watch?v=_hwb0-F1yKs). The PSAs, general information about research and additional information about the Building Trust project can be found at [http://ads.worlddealer.net/index.cfm?ad_id=301](http://ads.worlddealer.net/index.cfm?ad_id=301). All these media segments will be incorporated in the Building Trust curriculums.

**BUILDING TRUST BETWEEN MINORITIES AND RESEARCHERS**

The University of Maryland Center for Health Equity
A Research Center of Excellence on Minority Health Disparities
School of Public Health
University of Maryland
3302E SPH Building #255
College Park, MD 20742-2611
Office: 412-647-4349
Website: [http://www.healththequity.umd.edu/buildingtrust.asp](http://www.healththequity.umd.edu/buildingtrust.asp)

The project described was supported by Award Number 7RC2MD004766 from the National Institute on Minority Health and Health Disparities. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute on Minority Health and Health Disparities of the National Institutes of Health.

© 2010 All Rights Reserved Worldwide