RACIAL DISPARITIES IN HIV CARE AND OUTCOME:

A CALL FOR AN EVIDENCE-BASED RESPONSE

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RACIAL DISPARITIES IN HIV CARE AND OUTCOME: A CALL FOR AN EVIDENCE-BASED RESPONSE[1]

Introduction and Summary

Recent proposals to change HIV counseling and testing protocols rest on claims that current laws incorporating informed, written consent as a predicate to testing are outdated barriers to care. This reasoning characterizes HIV testing laws as a dated response to a past time when severe stigma, the population of white gay men regarded as primarily affected, and the lack of effective treatment warranted special pre-test counseling, proof of consent, and assurances of confidentiality.[2] Laws that require counseling before and after HIV testing, and a patient's written consent to testing and authorization to release identifiable results, the reasoning continues, are interfering with the testing and treatment that would eliminate racial disparities, and so need to be "modernized."[3]

This reasoning relies to a surprising extent on mischaracterizations of both AIDS' short history,[4] and of informed consent, a concept that in fact emerged only in recent decades that include the adoption of HIV testing laws.[5] Still, the question remains: will eliminating virtually all provider-patient communication, and written proof of informed consent, result in earlier, better and sustained access to HIV treatment and medical care, and better outcomes for people of color in this country?

The available evidence strongly indicates that the planned elimination of all pre-test counseling, informed consent, and written proof of such consent prior to HIV testing as a response to racial disparities in care is both unsupported and unsound. This is so because 1) the plan is *not* evidence-based, i.e., based on demonstrable evidence that counseling, consent and confidentiality procedures are in fact discouraging patient care; and 2) the evidence strongly suggests that in fact the proposals will *worsen* racial disparities in access to, and initiation and maintenance of, appropriate and life-prolonging treatment.

There is substantial, long-standing evidence of racial disparities in initiation and ongoing access to state of the art HIV/AIDS treatments that are mirrored across a variety of health conditions, all across the country. None of the evidence suggests that pre-test counseling and written proof of informed consent perpetuate stigma or are a barrier to care. However, *most of the evidence – even that produced by health provider interviews – shows that health care provider conduct, and the extent to which physicians establish a trusting relationship with patients, is closely connected to racial disparities in the initiation and continuation of life-saving HIV care.* Attempting to address the problem of racial disparities by promoting the very views and behaviors underlying the problem is, to say the least, counterproductive.

Policies and programs that counsel and work with patients to assess potential exposure to HIV and to encourage appropriate testing and voluntary care for themselves and their children are essential for ensuring an effective continuum of care. Removing all counseling and consent requirements, as a trade-off for the promise of streamlining and speeding introduction to care, is short-sighted. Building physician trust in the most hard-hit communities is a public health imperative. For people who already mistrust medical providers, elimination of pre-test counseling and proof of consent eliminates a critical juncture for fostering patient trust of a provider and the larger health care system. Despite the desire on all sides for an easy answer, the evidence suggests that speeding the testing process through elimination of all pre-test consultations between provider and patient ultimately will further delay real progress on the complex, continuing problem of racial disparities in HIV/AIDS diagnosis, care and outcomes.

Fortunately, the evidence also shows that there are a number of initiatives that likely would make a significant dent in these disparities, and in HIV-related stigma, consequently saving and improving many thousands of lives. Several of these could be accomplished with little more than a stroke of the legislative pen; others require a commitment to saving lives that is matched with a willingness to invest significant funding in the solution.

Evidence-Based Alternatives for Reducing Racial Disparities in HIV Testing, Care and Outcomes

- **Provide funding incentives to health care providers for interventions that demonstrably reduce barriers to HIV treatment and care, and that improve provider statistics on patient treatment initiation and patient retention.**

- **Institute regular, mandatory evaluation and training as appropriate for health care staff responsible for screening, treatment and referrals to ensure capacity in 1) the benefits and risks of HIV diagnosis and current HIV treatment options; 2) patient counseling and communication, based on available evidence of provider skills and characteristics that improve retention of marginalized populations with HIV in care.**

- **Design interventions to increase the participation of people of color in HIV testing and care that recognize and address patient/community perceptions of racism, stigma, provider inaccessibility, and other significant barriers to care.**

- **Expand training, recruiting and mentoring programs and goals to increase the number of African American and other minority infectious disease specialists in HIV/AIDS care.**

- **Increase support for innovative programs that combine the provision of drug and alcohol treatment services with antiretroviral therapy, and that otherwise improve health care access by reducing socio-cultural and geographic barriers.**

- **Increase federal funding and amend public policies that create barriers to care, such as 1) restrictions on ADAP funding and state-imposed income and benefit limits; 2) eligibility limitations and waiting period requirements that restrict Medicaid enrollment of low-income individuals with HIV and other debilitating illness.**

- **Amend or clarify state policies that perpetuate stigma by inappropriately targeting individuals with HIV for disparate treatment, such as 1) state licensing and infectious disease laws used to exclude people with HIV from barber, massage, and other trade schools and careers; 2) laws that mandate HIV testing as a punishment for individuals charged or convicted of certain crimes; and 3) state laws that use knowledge of one's HIV status as a basis for criminal prosecution or heightened criminal penalties. Similarly, no federal law should ever require states to establish HIV-specific civil and criminal penalties as a condition for receipt of federal financial assistance.**

- **Require and monitor the provision of 1) confidential, voluntary HIV and STD testing, and 2) treatment options reflective of current USPHS guidelines for initiation and continuation of antiretroviral treatment, in all federal prisons and as a condition of federal funding for state and local correctional facilities.**[6]

- **Federal and state proposals to expand and expedite HIV testing must provide funding to cover the costs of the testing, counseling, housing, treatment, and hospice care.**[7]

►**There is Substantial Evidence of Significant Racial Disparities in Access, Level of Intervention Offered, and Outcome Across a Broad Array of Health Conditions, Including HIV, in All Parts of the United States**

Despite dramatic improvements in the United States in overall health and life expectancy, racial and ethnic minorities have reaped significantly less than their share of these advances. [8] National data indicate that minority Americans, including New Yorkers,[9] have far poorer health outcomes than whites from preventable, treatable conditions such as cardiovascular disease, diabetes, asthma, cancer and HIV/AIDS.[10] Among the factors that contribute to this unacceptable situation, research has demonstrated that the primary cause is social determinants such as lower socioeconomic status, inadequate and unsafe housing, and racism; and the second is lack of access and the fact that people of color are more likely to be uninsured.[11]

However, considerable research over the last 20 years also has revealed that racial disparities continue in the actual quality of health care, even when controlling for social determinants and insurance.[12] Proof of disparities appear in everything from prescription of pain relievers to use of cardiac diagnostic and therapeutic procedures, treatment of pneumonia, treatment of congestive heart failure, to referral for renal transplantation and even immunizations and mammograms.[13] Recent research also confirms widespread racial -- and gender – disparities in the use of antiretrovirals to treat HIV disease, i.e., even after they present for testing, many women and people of color with HIV/AIDS are not offered antiretroviral therapy and other clinically appropriate care. For example, recent data produced by a multistate sample of HIV patients *already in care in major HIV primary care sites, including New York City*, revealed that *many eligible women and African American patients* still did not receive antiretroviral therapy.[14] The fact that in some states the disparity may be somewhat greater for HIV than other diseases is explained at least in part by the congruence of both the much higher association of intravenous drug use and homelessness with HIV/AIDS than diabetes and other diseases, and the measurable disinclination of physicians to initiate or continue HAART for HIV positive patients who are current or former IDUs.[15]

Evidence of this type of racial disparity for care provided to those *who already have tested positive and presented for care* has been duplicated in a number of studies.[16] An April, 2006 report on racial and ethnic disparities in breast cancer offers an instructive mirror image of racial differences in HIV care. Examining data from multiple mammography registries participating in the Breast Cancer Surveillance Consortium, the authors found that African American women, who have more advanced disease upon diagnosis and higher mortality rates that white women, were less likely to receive adequate mammography screening. Clearly there is no legal impediment of counseling, consent and confidentiality that is the cause of the different disease impact of breast cancer on African American women.

The example of newborn screening for HIV, and testing of pregnant women, while pointed to as support for the efficacy of eliminating counseling and specific consent,[17] appears to undermine the argument. Although perinatal transmission of HIV has been all but eliminated in this country,[18] only two states actually mandate newborn testing and most, including New York, have required counseling of pregnant women prior to testing. Data from the Perinatal Guidelines Project indicated that the vast majority of women in fact accept HIV testing if it is recommended by their health-care provider,[19] and also strongly suggest that "opt-out" approaches that eliminate counseling and proof of consent can result in substantial numbers of women not even knowing whether they had been tested.[20]

To date, government proposals to reduce racial disparities in HIV/AIDS care and outcomes do not appear to reference any research into the needs or perceptions of the communities they intend to serve. They ignore the significance of findings, in studies at urban public hospitals, that minority individuals favor routinely-offered HIV testing but have concerns about privacy; that fear and stigma commonly deter testing; and that distrust and misconceptions, particularly about the importance of testing, are very common.[21] The solutions they propose appear to reject the continuingly documented, wide-spread distrust of public health authorities among African Americans, and specifically HIV/AIDS conspiracy beliefs, that underscore the need of government and public health entities to take steps to build trust in black communities by acknowledging, and addressing, the origin of these beliefs and the current discrimination in the health care system.[22] Widely available research strongly suggests that racial disparities won't be resolved without consideration of the factors, including patients' trust in physicians, that directly affect their reliance on the health care system generally and their HIV care providers specifically.[23]

►A Growing Body of Evidence Shows that Physician Attitudes and Investment in Patient Relationships and Communication Play a Central Role in Racial Disparities in Disease Treatment and Outcomes, Including HIV/AIDS Diagnosis and Continuum of Care

While persistent racial disparities in health care have been common knowledge in the medical and public health communities for years, relatively little attention has been paid to the potential contribution of public health and provider behavior to such disparities.[24]

Responding two years ago to a series of articles on racial/ethnic bias in health care, Dr. Philomina N. Gwanfoghe, of the Missouri Department of Health and Senior Services, commented:

> It has been repeatedly demonstrated that certain racial/ethnic minority patients receive diagnosis and treatment recommendations differing from those of similar white patients…[E]ven when their insurance and income are the same as … whites, minorities often receive fewer tests and less sophisticated treatment for a panoply of ailments, including heart disease, cancer, diabetes and HIV/AIDS…[The authors] suggest that patients could receive training in effective doctor-patient interaction. Oddly, the most important issue related to such training is not addressed: **Why do black and economically disadvantaged patients need to do something extra…in order to receive the diagnosis and treatment they deserve by virtue of being patients?...Let us start at the right place. Considering that health care providers, rather than patients, are the more powerful actors in clinical encounters, providers' behaviors are a more important target for intervention efforts.[25]**

Dr. Gwanfoghe's comments merit serious consideration; after all, studies have established that patients' trust of their physicians is strongly related to their use of preventive services, adherence to treatment recommendations, and continued participation in care.[26] Why, after years of serious racial disparities in HIV/AIDS care and other diseases that disproportionately kill people of color, do proposed solutions to these disparities fail to address the developing body of evidence on the actual causes? For years, there has been sufficient evidence supporting the hypothesis that provider behavior contributes to racial disparities in care to warrant a more intensive research and policy focus on solutions that address it.[27] Why focus on "streamlining" services to the affected communities, when the beliefs and conduct of providers whose services are central to a different health outcome "may prove to be the most promising targets for intervention" to reduce disparities in care?[28]

Perhaps current proposals reflect fear of funding shortfalls, the belief that eliminating HIV counseling and written consent are cost-free, and the perception that the complex issues of race and class in care provision are too intractable for quick improvement. Even so, proposed solutions have yet to include the support of any evidence that patient counseling and written consent play a role in these disparities. In fact, the evidence demonstrates something of the opposite, i.e., that doctor experience and investment in the physician-patient relationship plays a central role in the access of marginalized populations to HIV antiretroviral therapy.[29]

For example, virtually every study that has considered the issue overwhelmingly attributed delays in HIV testing of pregnant women to a lack of prenatal care, and to physician disinclination to offer testing due to inadequate training or understanding of when to offer testing, time pressures, and discomfort with discussing sexual issues with women or in otherwise complying with current standards of HIV counseling. In turn, studies examining delays and obstacles in seeking care for disadvantaged (and predominantly minority) clients -- with one study showing that the majority had no regular source of care -- attributed these barriers largely to lack of insurance, lack of transportation, exposure to violence, lack of sick leave and lack of affordable child care.[30] These factors have been repeatedly reported and long known, yet continue to remain mostly unacknowledged and unaddressed by policy makers and in public health proposals affecting AIDS care.

Changing legal protections that ensure a basic level of provider-patient interaction and patient involvement in care decisions is a proposal that may be attractive for its deceptive simplicity. Unfortunately, it is yet another "solution" that addresses an epidemic increasingly and disproportionately affecting racial minorities by accommodating doctor disinclination to consult with patients in order to "improve patient flow" and further reduce patient involvement in health care decision-making.[31]

Recent studies looking explicitly at barriers to the use of antiretroviral therapy have repeatedly found that physician treatment attitudes and physician-related characteristics not only can serve as a significant barrier to access, but also are *strongly associated with better access, adherence, and retention in treatment;* in fact, actual willingness to initiate HAART has been associated with patient trust in their physician.[32] In short, physicians who spend the time to establish a trusting, respectful attitude are patient magnets; those who don't are patient repellants. All available evidence suggests that the plan to eliminate pre-test provider-patient conversations that are portals to establishing trust will exacerbate, rather than resolve, racial dissatisfaction and disparities in HIV care and outcomes.

► Competent HIV Pre-Test Counseling and Securing Proof of Informed Consent Is More Likely to Reduce, Rather Than Perpetuate, Racial Disparities, Stigma and Barriers to HIV Testing and Care

Some have argued that pre-test counseling focused on patient understanding and consent in HIV testing perpetuates stigma because it departs from the typical approach to disease diagnosis and testing. It even has been posited that too much information related to both the physical and social consequences of HIV infection (e.g., eventual reliance on powerful, often toxic drugs; the lack of a cure and the life-long need to monitor disease progress and prevent transmission; disqualification for various forms of insurance and career options; exposure in many states to criminal prosecution for all forms of sexual activity, etc.) will inappropriately discourage people of color from getting tested.

As the discussion above indicates, there is no evidence that information about HIV and testing, or additional contact with a health care provider prior to testing, has any negative impact on testing decisions or subsequent care. In fact, in view of the evidence that perceptions and fears prior to counseling disproportionately militate against HIV testing in people of color communities,[33] supportive counseling can serve a critical function in reducing mistrust and encouraging engagement in care. Lacking support in the research literature, the argument also does not accurately reflect the context in which HIV testing laws largely were adopted, including the treatment landscape at the time, or the developing notion of patient autonomy and involvement and care accelerated by the HIV epidemic in this country.[34]

Stigma is not caused or reinforced by how testing is conducted, but by its association with sex (primarily gay sex)[35] and intravenous drug use; the fact that it is life-long and incurable; the fact that both the disease and its long-term treatment inevitably produces recognizable physical manifestations; and because it continues to be the basis for significant disparate treatment both socially and economically. Stigma is reflected in the continuing and wide-spread ostracizing of those who are infected, within their social networks and through their singling out for exceptional treatment in criminal and civil law and exclusion from participation in program and employment opportunities open to similarly qualified individuals who have not tested HIV positive. The continuing stigma connected with being HIV positive is reflected in present day events like the call by a New York City official – in 2006 – for adoption of a law making felons of those who test HIV positive and engage in sexual activity, calling HIV seroconversion a "death sentence."[36]

Supporters of the elimination of counseling and proof of consent prior to HIV testing argue that these practices reflect "exceptionalism" in the disease's treatment inconsistent with "traditional" public health laws. However, these laws largely were adopted or revised decades before the HIV laws that are the target of this "modernization" effort, at a time when physician resistance to patient autonomy was less constrained by patient activism. It is true that an unprecedented, even exceptional, level of patient involvement in medical care decision-making became a hallmark of the AIDS treatment movement. However, the labeling of this development as "exceptionalism" overlooks the fact that state HIV testing and confidentiality laws, adopted more recently than infectious disease control statutes governing most other health conditions, reflect more than the past and continuing reality of HIV stigma and its real life consequences. They also incorporate the evolving understanding of a patient's right to information and autonomy in making treatment decisions, a right undermined by proposals for a reversion to the outdated "doctor knows best—you don't need to know" approach.[37]

Eliminating HIV counseling and consent requirements responds to the demands of some doctors to eliminate as many mandates for patient contact, record-keeping or reporting as possible. However, most doctors in HIV care likely also would confirm that the federal and state HIV reporting requirements are more burdensome than allowing a counseled patient to sign a form. With most patients confronting multiple forms at every health care encounter, it is ironic that the one form relevant to protecting their autonomy is the one that health care providers purportedly find burdensome, particularly when there are multiple creative, effective ways to encourage informed testing and securing patient consent that involve little physician time.[38]

Replacing information and proof of consent with an "opt-out" approach to HIV testing is in fact unlike the pre-testing discussion utilized by most qualified physicians when dealing with an anxiety-producing health condition. It also puts the patient in the typically untenable position of refusing, or disagreeing with, a doctor's diagnosis and treatment plan, as opposed to an informed choice following a discussion of options. An "opt-out" approach ensures that some patients will be tested without their full knowledge. Studies also show that the failure to match patient treatment with their preferences (including their attitudes to all manner or risk) has a negative impact on decisions to access and continue care; in other words, accommodation of physician preferences in the delivery of care over patient preferences and needs is associated with lower rates of care.[39]

Routine HIV testing with a right of refusal is inconsistent with modern principles of informed consent.[40] While this approach may serve physician convenience in the short-term, it also accommodates the eroded quality of care associated with the shift to managed care.[41] It also in no way reflects the needs or desires of the people lost to care who frequently explain their health care avoidance by reference to highly negative encounters with health care systems they experience as demeaning or patronizing.[42]
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Legal and ethical principles dictate that informed consent remain an integral element of HIV-related education, counseling, testing, and treatment.[43] The role of quality pre-test counseling, and the patient's informed consent -- and the absence of legitimate reasons to treat people of color differently in this respect as compared with other affected populations or even the diagnosis of other incurable, chronic diseases -- is well established, particularly in perinatal care:

> [C]ourts do not consider informed consent a luxury, to be abandoned because it is perceived as too burdensome by physicians. There is no valid reason to eliminate the requirement for pregnant women. Indeed, obtaining a pregnant woman's consent and counseling her is particularly important. The sooner she is informed about the advantages and disadvantages of testing and available treatments, the more likely she is to make decisions that will ultimately benefit herself and her

> child. In addition, requiring that testing be done only with her specific and informed consent will enhance the trust necessary for establishing a collaborative relationship with the physician.[44]

Approaches to care which dismiss the importance of patient knowledge, acceptance of, and involvement in treatment strategies invariably also underestimate the central role of patients in their care and the treatment of their children, and the very basic practical considerations affecting that care and treatment. Therapeutic interventions addressing HIV testing and care are not a one-shot enterprise; to work, they must engage patients for the long term.[45] It is unlikely that we will reduce racial disparities in the HIV/AIDS epidemic by using these sad statistics as a basis to streamline testing and more data collection that does nothing to address the underlying problems. As one physician expert in this area recently concluded:

> Minority patients are disproportionately affected by the HIV/AIDS epidemic. In addition, however, disparities in care that have negatively affected minorities with HIV/AIDS have been repeatedly documented. An approach to care that uses a cultural competence framework, enhances communication between minority patients and their providers, endeavors to use a more diverse array of staff members, proactively enhances the likelihood of receipt of HAART, and uses an evidence-based approach to thinking about adherence will improve the likelihood that minority patients will engage in care, be satisfied with care, and have positive HIV/AIDS outcomes.[46]

Accordingly, we offer the recommendations outlined above as an alternative starting point for taking a serious, more promising, approach to racial disparities in HIV diagnosis, care and outcomes.

Catherine Hanssens, Executive Director
The Center for HIV Law and Policy
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[1] We gratefully acknowledge the assistance of John Falkenberg, RN, and Elliot Turner, Brooklyn Law School legal intern, for their significant research contributions to the analysis and proposals here.

[2] *See* New York Dep't of Health and Mental Hygiene, Memorandum in Support of proposed legislation, "An Act to amend the public health law, in relation to improving the care of persons living with HIV/AIDS," at http://www.nyc.gov/html/doh/downloads/pdf/ah/ah-memo-support.pdf .

[3] *Id.*

[4] The early identification of *white* gay men as the central victims of HIV was more a product of the same racial disparities and homophobia that bedevil HIV treatment to this day than a fact of epidemiology. And in 1989, when NY's HIV testing and confidentiality law was adopted, HIV diagnosis for initiating life-saving PCP prophylaxis and AZT therapy was considered critically important. See http://www.accessdata.fda.gov/scripts/cder/ob/docs/ obdetail.cfm?Appl_No=019887 &TABLE1=OB_Rx and http://www.aegis.com/pubs/beta/1989/ BETA0403.html (regarding 1989 approval of pentamadine to prevent PCP; information on prevention of pneumocystic carinii pneumonia); http://www.aidsmap.com/en/docs/52923980-211B-48E9-80A1-A58985FF44ED.asp; 322 N. ENG. J. MED. 941-949 (4/5/1990)(for information on approval and recommendation of AZT monotherapy in 1987 for symptomatic AIDS, and expansion in 1990 to include CD4 counts below 500) .

[5] *See* B. L. Atwell, *The Modern Age of Informed Consent*, 40 U. RICH. L. REV. 591 (Jan. 2006). For example, NY's venereal disease law hasn't been substantially revised since 1953, 25 years before the NY HIV testing law was considered and adopted, and before the term "informed consent" and modern concepts of patient autonomy and active participation in health care decision-making started to be reflected in local law. L. Golec, Association of Clinical Research Professionals, *Are You Truly Informed About Informed Consent?*, http://www.acrpnet.org/education/hstudy/textfall04.html. (Noting that prior to

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1957, the tern “informed consent” had never been used.)See McKinney’s Consolidated Laws of NY, Public Health Law, Chapter 45, Article 23 , Section 2300, L. 1953, c. 879 (2001)(regarding care and treatment of venereal disease).

[6] In view of the fact that roughly 25% of those with HIV cycle through the prison system, and in view of the disproportionate representation of racial minorities in this subgroup, the failure to institute and enforce the prevailing standard of HIV testing and care access in correctional facilities across the country is inexplicable. As has been pointed out in testimony and reports for nearly two decades, these facilities represent an extraordinary public health opportunity, a literally captive population, and a government obligation that remains miserably unaddressed. We believe that any serious attempt to redress racial disparities in HIV care, and related epidemics such as hepatitis C, must include a concrete plan for correcting this considerable omission in tackling these diseases.

[7] National Conference on State Legislatures**,** *2005-2006 Policies for the Jurisdiction of the Health Committee: Acquired Immune Deficiency Syndrome/HIV-Infection*, accessed at **http://www.ncsl.org/statefed/HEALTH.HTM#aids** (April 18, 2006).

[8] Joseph R. Betancount, MD, MPA, Angela W. Maina, BS, *The Institute of Medicine Report “Unequal Treatment”: Implications for Academic Health Centers*, 71 THE MT.SINAI J. OF MED. 314-321 (Oct. 2004).

[9] New York City Dep’t of Health and Mental Hygiene, *Health Disparities in New YorkCity* (2004).

[10] Betancount et al., *The Institute of Medicine Report “Unequal Treatment”: Implications for Academic Health Centers, supra.*

[11] *Id.* at 315.

[12] *Id.* at 315.

[13] *Id.* at 315; *See also, e.g.*, D.R. Harris, R. Andrews, A. Elixhauser, *Racial and gender differences in Use of Procedures for Black and White Hospitalized Adults*, 7 ETHNICITY DIS. 91-105 (1997); K.A. Schulman, J.A. Berlin, W. Harless et al., *The Effect of Race and Sex on Physicians’ Recommendations for Cardiac Catheterization*, 340 N. ENG. J. OF MED. 618-626 (1999); K.H. Todd, N. Samaroo, J.R. Hoffman, Ethnicity as a Risk Factor for Inadequate Emergency Department Analgesia, 269 J.A.M.A. 1537-1539 (1993); *see also* Megan Rauscher, Reuters Health, *Blacks With Colorectal Cancer Less Likely to Get Adjuvant Chemotherapy,* (4/3/2006).

[14] Kelly A. Gebo, M.D., Richard D. Moore, M.D., and John A. Fleishman, Ph.D., *Racial and Gender Disparities in Receipt of Highly Active Antiretroviral Therapy Persist in a Multistate Sample of HIV Patients in 2001* According to the authors, “information on socioeconomic disparities in care is needed by Federal and State policy makers to help ensure that all persons with HIV disease (regardless of their gender, race, ethnicity, income or geographic location) have access to appropriate health care services. In view of the rapidity of change in HIV related treatments and services, policy makers need an established, ongoing mechanism to collect relevant data and to provide analyses of current resource utilization parameters in a timely manner… Therefore in 1999, the HIV Research Network (HIVRN), a network of providers of medical care to patients with HIV infection, was formed. The network members collaborate on research to provide policy makers and researchers with timely information about access to, utilization, cost, quality, and safety of HIV care.” Members of the HIVRN that participate in and contribute data to this research include several major medical facilities in New York City. *See* http://hopkins-aids.edu/publication/report/nov03_2.html

[15] V.E.Stone, MD, MPH, Dir., Women’s HIV/AIDS Program, Assoc. Chief, G.M.U, Massachusetts General Hospital, Assoc. Prof. of Med., Harvard Medical School, *Disparities in HIV/AIDS by Race/Ethnicity*, (2006) http://www.med.unc.edu/ome/Zollicoffer_Presentation_2006.pdf

[16] *E.g.* W.E. Cunningham, L.E., Markson, R.M. Andersen, et. Al, *Prevalence and Predictors of Highly Active Antiretroviral Therapy Use IN patients With HIV infection in the United States*,

[17] *E.g,* T.R. Frieden, M Das-Douglas, S.E. Kellerman, K.j. Henning, *Applying Public Health Principles to the HIV Epidemic*, 353 N. ENG. J. OF MED. 2397, 2399 (Dec. 1, 2005).

[18] *Id.* at 2399.

[19] M.I. Fernandez, T.E. Wilson, K.A. Ethier et al. *Acceptance of HIV testing during prenatal care*, 115 Public Health Rep. 460-468 (2000).

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[20] Centers for Disease Control and Prevention, *HIV Testing of Pregnant Women -- United States and Canada, 1998 – 2001*, 51 MMWR 1013-1016 (November 15, 2002). Interviewers for the CDC's Pregnancy Risk Assessment Monitoring System (PRAMS) found that 16% of pregnant women tested in Arkansas, one of the two states with the type of "opt-out" HIV testing now being pushed, didn't even know whether they had been tested for HIV.

[21] A.B. Hutchinson, G. Corbie-Smith, S.B. Thomas, S. Mohanon, C. del Rio, *Understanding the Patient's Perspective on Rapid HIV Testing in an Inner-City Urgent Care Center*, 16 AIDS EDUC. PREV. 101-114 (April 2004).

[22] *E.g.*, L.M. Bogart, S. Thorburn, *Are HIV/AIDS Conspiracy Beliefs A Barrier To HIV Prevention Among African Americans?*, 38 J. AIDS 213-218 (Feb. 1 2005); ., M.W. Ross, J. E. Essien, S. Torres, *Conspiracy Beliefs About the Origin of HIV/AIDS in Four Racial/Ethnic Groups*, 41 J.AIDS 342-344 (March 2006).

[23] *See* J.L. Murray-Garcia, J. V. Selby, J. Schmittdiel, K Grumbach, C.P. Quesenberry, *Racial and Ethnic Differences in a Patient Survey: Patients' Values, Ratings, and Reports Regarding Physician Primary Care Performance in a Large Health Maintenance Organization*, 38 MEDICAL CARE. 300-310 (March 2000); D.H. Thom, M. A. Hall, L. G. Pawlson, *Measuring Patients' Trust in Physicians When Assessing Quality of Care*, 23 HEALTH AFFAIRS 124-132 (2004).

[24] M. van Ryn, S.S. Fu, *Paved UIT Good Intentions: Do Public Health and Human Service Provders Contribute to Racial/Ethnic Disparities in Health?*, 93 AM. J. PUB. HEALTH 248-255 (February 2003).

[25] Philomina N. Gwanfoghe, Letters, *The Reality of Racial/Ethnic Bias in Health Care,* 93 AMERICAN JOURNAL OF PUBLIC HEALTH1984 (Dec. 2003).

[26] D.H. Thom, Mark A. Hall, L. G. Pawlson, *Measuring Patients' Trust I Physicians When Assessing Quality of Care,"* 23 HEALTH AFFAIRS 124-132 (2004).

[27] M. van Ryn, *Research on the Provider Contribution To Race/Ethnicity Disparities in Medical Care*, 40 MEDICAL CARE, Supplement: 1-140 – 1-151 (Jan. 2002).

[28] *Id.*

[29] Evan Wood et al., *Expanding Access to HIV Antiretroviral Therapy Among Marginalized Populations in the Developed World*, 17 AIDS 2419-2427 (May 14, 2003).

[30] *See, e.g.,* Kimberly J. Rask, et al., *Obstacles Predicting Lack of a Regular Provider and Delays in Seeking Care for Patients at an Urban Hospital*, 271 JAMA 1931-33 (1994); D.B. Dutton, *Explaining the low use of health services by the poor: costs, attitudes or delivery systems,* 43 Am. Soc. Rev. 348-68 (1978). Curiously, the Rask study also found that living in supervised settings, such as a shelter, was also a predictor for delayed access to care, underscoring the inadequacies and piece-meal nature of social services for the poor.

[31] As a Columbia University professor, internist and anesthesiologist recently put it:

> Doctors know that you cannot provide compassion in seven-minute aliquots. The medical establishment has, many of us feel, simply rolled over and gone along to get along. It has sacrificed patients' best interests…If you cannot get more than a seven-minute face-to-face encounter with your doctor, he needs fewer patients…Restoring the doctor-patient relationship will not save anyone any money. But…[t]here are other ways to curtail health care costs…None of them requires patients to sacrifice their self-respect…**The doctor-patient relationship is critical to the integrity of the health care system. It is not disposable**…

Peter Salgo, Op Ed, *The Doctor Will See You for Exactly Seven Minutes*, THE NY TIMES, 3/22/2006.

[32] *E.g*, Evan Wood et al., *Expanding Access to HIV Antiretroviral Therapy Among Marginalized Populations in the Developed World*, 17 AIDS 2419-2427 (May 14, 2003); F.L. Altice, F. Mostashari, G.H. Friedland, *Trust and the Acceptance of and Adherence to Antiretroviral Therapy*, 28 J. ACQUIR. IMMUNE DEFIC. SYNDROME 47-58 (2001); K.J. Roberts, *Physician-Patient Relationships, patient satisfaction, and antiretroviral medication Adherence Among HIV-Infected Adults Attending a Public Health Clinic*, 16 AIDS PATIENT CARE STDS 43-50 (2002).

[33] *See., e.g.*, M.W. Ross, J. E. Essien, S. Torres, *Conspiracy Beliefs About the Origin of HIV/AIDS in Four RacialEthnic Groups*, 41 J.AIDS 342-344 (March 2006); V.E.Stone, MD, MPH, Dir., Women's

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HIV/AIDS Program, Assoc. Chief, G.M.U, Massachusetts General Hospital, Assoc. Prof. of Med., Harvard Medical School, *Disparities in HIV/AIDS by Race/Ethnicity*, (2006), accessed 4/20/2006, at http://www.med.unc.edu/ome/Zollicoffer_Presentation_2006.pdf.

[34] *See* footnote 4, *supra*.

[35] L.M. Takahashi, *Stigmatization, HIV/AIDS, and Communities of Color: Exploring Response to Human Service Facilities* 3 Health Place 197-199 (Sept. 1997)(finding that community interviewees view of stigma association with HIV was the social construction of "HIV/AIDS as homosexuality.")

[36] P. Vallone, Jr., *Prosecute HIV?*, N.Y. DAILY NEWS (March 16, 2006)

[37] *See, e.g.,* B. L. Atwell, *The Modern Age of Informed Consent*, 40 U. RICH. L. REV. 591 (Jan. 2006).

[38] New York State's recent streamlining of HIV counseling and testing, for e.g., keeps informed written consent in place, with many providers using a waiting room video about HIV testing and treatment that ensures patient understanding while decreasing time needed to ensure that HIV testing is informed and voluntary, and that the patient is encouraged into care.

[39] *See* Michael J. Barry, *Involving Patients in Medical Decisions -- How Can Physicians Do Better?*, 282 JAMA 2356-2357 (Dec. 1999).

[40] *See* B. L. Atwell, *The Modern Age of Informed Consent*, 40 U. RICH. L. REV. 591 (Jan. 2006).

[41] Peter Salgo, Op Ed, *The Doctor Will See You for Exactly Seven Minutes*, THE NY TIMES, 3/22/2006 (addressing pressures on doctors to "keep things moving" and consequent impact on patient care).

[42] Several focus groups conducted by SMART with client groups revealed a commonality to those who had stopped seeing health care providers: the physician's failure to answer questions adequately, a lack of compassion or understanding of the patient, and the rushed nature of the health care interaction after routinely extended waits to see a physician. This focus group feedback is consistent with multiple studies that have found both that minority patients are less satisfied with their HIV care than are other patients, and that inadequate patient-provider communication is a consistent factor in the dissatisfaction reported in these studies. *E.g.,* Valerie Stone, *Optimizing the Care of Minority Patients with HIV/AIDS*, 38 CID 400-404 (Feb 1. 2004).

[43] Elizabeth B. Cooper, *HIV Disease in Pregnancy: Ethics, Law and Policy*, 24 OBSTET. GYNECOL. CLIN. NORTH AM. 899-910 (1997)(Noting also that undervaluing and underemphasizing patient counseling and education is likely to backfire, and that presumption that parent will act in child's best interest, accepted in analogous contexts, should be axiomatic in the development of HIV policy).

[44] Canadian HIV/AIDS Legal Network, "HIV Testing and Pregnancy," http://www.aidslaw.ca/Maincontent/issues/testing/e-info-ta14.htm

[45] An academic commentator who takes credit for popularization of the term "HIV exceptionalism," writing a decade ago on the then-current treatment regimen of AZT to reduce the vertical transmission of HIV from mother to infant put it plainly: "The pragmatic aspects alone of the treatment regimen defined in Protocol 076 make the prospect of therapy without the full cooperation of infected pregnant women difficult to contemplate. Even if one sought to mandate the use of an intravenous dose of zidovudine during delivery, how could one enforce a daily regimen of five doses of zidovudine during the second and third trimesters of pregnancy? Would anything short of incarceration make such treatment possible?" Ronald Bayer, *Ethical Challenges Posed by Zidovudine Treatment to Reduce Vertical Transmission of HIV*, 331 N. ENG. J. OF MEDICINE 1223, 1225 (Nov. 3, 1994).

[46] V.E. Stone, *Optimizing the Care of Minority Patients with HIV/AIDS*, 38 CID 400, 403 (February 1, 2004).