

**Illustrating and analyzing the processes of multi-institutional collaboration: Lessons learnt
at Howard University Hospital**

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Abstract:

Multi-institutional collaboration offers a promising approach to the dissemination of resources for capacity building and the improvement of the training of new investigators and residents, especially in areas of novel curricular content. Physicians should keep pace with the rapid growth of curricular content in an era of restricted resources. Such collaborations, in which educational entities work together and share resources and infrastructure, have been employed in health care to improve quality of care, capacity building, disparity reduction, and resident training. This paper examines a federally funded multi-institutional collaboration for the project STRIDE (Seek, Treat, Reach to Identify Pretrial Defendants Enhancement) between Yale University, George Mason University (GMU), and Howard University, a Historically Black University.

The STRIDE study collaboration focused on mental health, opioid addiction, and infectious disease/HIV among African Americans involved in CJS (Criminal Justice System). We discuss some of the challenges and benefits of collaborative research projects conducted at Historically Black Colleges and University (HBCUs) and highlight the educational opportunities created by such collaborations for residents and other trainees, leading to the development of independent investigators through multi-institutional, structured collaborative research. We identify some unique challenges such as substance use, race, stigma, incarceration among participants, and the cultural and power difference between participating institutions, and thereby address these issues and how it impacted the course of the multi-institutional collaborative effort.

Introduction

It has long been recognized that despite an often greater burden of disease, people from minority groups are under-represented in clinical and health research. (Hussain-Gambles et al 2006) This can seriously limit the validity and generalizability of biomedical research and may have significant negative effect on the allocation of resources for services and research. Research involving minority groups, particularly African Americans, is also relevant to the majority 'white' population, as it increases understanding of the etiology and management of long-term conditions (Taylor AL, Ziesche S et al 2004), through increasing awareness of diversity and its implication for policy and practice, by improving access to dialogue with specific communities, and by highlighting the need for holistic approaches to managing illnesses.

Reasons for exclusion of minority groups are complex and could be attributed to multiple factors, such as subject preference, researcher bias, and societal factors. It is not clear whether the real issue is one of deliberate exclusion, unconscious racial biases, non-participation by minority groups, or a mixture of all of these factors. Indeed, recent studies have highlighted that minority groups are willing to participate in research if the study has direct relevance to them and their community, and if they are approached with sensitivity and if they are given clear explanations of what participation involves (Redwood, 2013). Furthermore, there is evidence from US-based research that non-participation may be related to the lack of commitment to ensuring good access to health research (Wendler, et al. 2005). Stereotypical and negative attitudes by researchers can influence decisions of minority groups for research participation. For instance, if researchers believe those with poor English

language skills may also lack adequate housing or transport, and therefore are more likely to have difficulty in keeping appointments or complying with the study protocol, such attitudes could clearly limit minority representation in research (Lo B, 2008).

In addition to the under-representation of minority population in clinical research, minority researchers are less likely to be successful in obtaining grant funding. One study showed that black applicants for NIH funding were about two-thirds as likely as white applicants to receive grants during the years 2000–2006, even when accounting for several factors, such as applicant's educational background, previous research awards, publication record, and training. This study found that black applicants remain 10 percentage points less likely than whites to be awarded NIH research funding. (D. K. Ginther et al 2011).

Although minority communities in the United States have grown rapidly, their representation in the scientific enterprise remains low (Guillermo Bernal et al 2009). An example of such underrepresentation can be seen in a National Advisory Mental Health Council report, which noted that in 1999, few minority investigators submitted research applications, and even fewer were funded. Of the total applications, the National Institutes of Health (NIH) received in 2002, only 0.8% were awarded to African Americans, 2.3% to Latinos, and 0.1% to Native Americans. Overall, only 3.2% of all research and program grants were awarded to these minorities, who accounted for 25% of the US population (Guillermo Bernal et al 2009). This report concludes that current and projected numbers of ethnic-minority researchers are insufficient to meet the needs of the science workforce.

One model to increase minority participation in research is through multi-institutional research. One model to improve diversity in biomedical research is through collaboration with institutes that have excellent research infrastructure and are thus likely to be successful in grant making, and collaboration with relatively resource deficient institutions that are serving a large minority population, but may not have the grant funding necessary to carry out extensive biomedical research. In this model, one institution can provide the research and technical expertise and the other institution can provide access to minority populations and staff. Implicit in this model is the assumption that the host institution will benefit from the capacity building and training of its staff during the research endeavor.

Longitudinal multi-center studies are complex enterprises, yet represent an essential approach for addressing the research gap (Mary Pat Moeller 2015). This is especially more challenging when multiple institutes work together to achieve the best outcome with limited resources/funding. Research indicates that increased investment in clinical research at HBCUs could benefit communities throughout the country (Timothy P et al 2009). Unfortunately, support from the federal government is severely deficient. From 1993 to 2002, total federal funding increased by 40% for all academic institutions, but only 24% for HBCUs (Minor JT 2008). During the last decade, HUH (Howard University Hospital) has successfully participated in various such collaborative efforts with mostly positive results.

HUH has played a unique role in efforts to reduce disparities by training and promoting minority health care researchers. HUH was built on the foundation of Freedmen's Hospital and Asylum, which cared for freed,

disabled, and aged blacks. In 1868, after the Civil War, Freedmen's Hospital became the teaching hospital of Howard University Medical School. In 1909, a new 278-bed Freedmen's Hospital was erected. In 1975, the current and modern University Hospital was opened. For many years, HUH was the only Carnegie I research intensive institution, and has trained more African Americans with professional or doctoral degrees than any other institution. Howard University Hospital is situated in Northeast Washington DC and is the main provider of indigent healthcare in Washington, DC, a city that faces some unique healthcare challenges. The city has been historically predominantly African American, but lately, the population dynamics are changing, with a large influx of younger Whites and Hispanics causing the so called "gentrification" of many neighborhoods.

The highest rates in the nation of people living with HIV can be found in the District of Columbia, at a rate of 3.2% with 73% of people living with HIV being African American (CDC, 2012). Opioid dependence (i.e. heroin) is associated with adverse medical/ psychosocial consequences, risk of HIV transmission through unprotected sex, or sharing needles used for intravenous illicit drug use. In addition, the prevalence of HIV infection is at least four times higher in the incarcerated population than non-incarcerated population (Beckwith et al 2010). Opioids are involved in 14.8% of all deaths following prison release (Washington State Dept. of Corrections- Binswanger, 2013)

HUH has been at the forefront of combating both the HIV and the opiate use epidemic in Washington DC. Howard University Hospital CIDMAR (Center for Infectious Disease Management and Research) is a multi-specialty clinic that offers outpatient infectious disease consultations and state of the art HIV care to vulnerable patients and

plays an important role in health and well-being of this marginalized patient population.

STRIDE Study

This study STRIDE was a part of NIDA STTR (Seek, Test, Treat Retain) initiative. This study was supported by a grant from the NIDA (National Institute on Drug Abuse) and was done at HUH from 2012 to 2015. This study was conducted within a collaboration among George Mason University (GMU), HUH, and Yale School of Medicine. This study tested the use of Buprenorphine (BUP), an evidence-based substance abuse treatment among opioid dependent HIV positive pretrial defendants and offenders and its impact on criminal justice involvement (CJS). The study carried out a placebo- controlled, randomized trial of BUP among HIV positive opioid addicts involved in CJS (Criminal Justice System). This model evaluated the impact of BUP treatment and other strategies (behavioral and adherence to treatment) and co-morbidities (substance use disorder, mental illness, homelessness) among the HIV positive involved in pretrial, probation, and correctional settings. The study had the following aims: 1) to improve HIV treatment outcome, including higher proportion of subjects initiating ART and VL <400, increased CD4 counts and retention in HIV care. 2) To improve opioid treatment outcomes, including longer time to opioid relapse and higher proportion of opioid negative urine tests. 3) To reduce drug and sex-related HIV risk behavior. 4) To improve time to re-arrest and re-incarceration, leading to a lower number of incarceration, thereby decreasing involvement in the CJS.

At Howard, most of psychiatry residents are minority or international medical graduates; therefore, cultural competency has assumed an ever increasing role in our curriculum (Malik M, 2013). Several PGY-4 residents'

joined project STRIDE as a part of research training. Residents were trained by PIs (Principal Investigators) on clinical psychiatric assessments, psychometric scales, detox, and randomization processes. Although project STRIDE provided excellent learning opportunities to residents, involvement of residents in writing research abstracts and publications was minimal. We noticed that there is a need of more structured research training program to assist on writing research abstracts, proposals, and manuscripts. We determined that the best approach for achieving this goal would be by establishing an effective research certification program that promotes mentorship among collaborative institutes.

Challenges at the host site (Howard University Hospital)

STRIDE Recruitment

Study participants were primarily recruited at Howard University. Recruiting of opioid dependent HIV positive subjects was one of the leading challenges for the STRIDE project. There were various factors associated with low recruitment, such as stigma, discrimination, reluctance to engage in the treatment, poor psychosocial support, and involvement in the CJS.

To address this challenge, the STRIDE project implemented an incentive program for the enrolled study participants to recruit members of their social networks for testing and substance use treatment. This program, however, was not very successful due to multiple reasons. The biggest concern that participants had expressed was that by referring a friend to the study, they would in turn disclose their own HIV status. The fear of stigma, discrimination, and lack of

confidentiality led to low referrals from the existing participants in this study.

The STRIDE recruiters' job was not simple. Indeed, it was a complicated, time consuming task to recruit patients. As a recruitment team, staff were trained on how to observe people and environments, on identifying the right times to talk to people, and on how to talk to people in a non-judgmental way. Recruiters spent considerable time and risk going into abandoned and unsafe buildings in DC to track down intravenous drug users and HIV positive individuals who may be willing to participate in the STRIDE project.

It was challenging to convince people to sign up for HIV-research studies, particularly when addressing combined substance use and HIV. It was important for our recruitment team to build relationships and talk about the various aspects of the study by elaborating on eligibility criteria, and explaining the step by step process of the psychiatric, medical, and psychological services participants would receive if successfully enrolled in the study.

Continuous illicit drug use and diversion

While on Suboxone treatment, all STRIDE study participants were encouraged to attend CBT (Cognitive Behavioral Therapy) groups on a weekly basis for the first three months, and once per month afterwards. All participants were advised to stay drug free while participating in this study. Despite recommendations from clinicians, some participants demonstrated continuous use of illicit drugs and presented with either opioid positive or multiple drug positive urine. When participants refused to undertake urine testing, the swab method was used for drug testing. Drug diversion was also very common, and some participants were arrested due to drug diversion. This came to the attention of study staff when they were notified by criminal

justice staff inquiring about frequency and dosage of Suboxone.

Challenges of integrating STRIDE in CJS (Criminal Justice System)

The STRIDE project experienced challenges of integrating the STTR (Seek, Test, Treat, Retain) strategy in the CJS. Several participants were involved in probation and pretrial services, causing interruptions of their daily lives. As a result, their legal status varied regularly, which affected their access to or engagement in medical or psychiatric care. In general, pretrial services and community correctional agencies are not mandated constitutionally to provide medical care or to address health conditions like HIV, even if the same risky behavior may impact criminal conduct significantly.

Continuous arrest/ incarceration and difficulty with data collection from CJS

During the study participation, most participants reported that illicit heroin was readily available at a low cost in the greater DC metropolitan area. This led to high rates of arrest and incarceration in the area. When a participant was serving time in prison, she or he would not be automatically disenrolled from the study. We contacted local prisons and requested access to the prison facility so that the subject could continue to receive study interviews- for which they agreed. One of the challenges faced occurred when participants were arrested and sent to remote prisons, where we had no access to participants to conduct research interviews and collect data. In these circumstances, we utilized the VINELink website- an online portal network that keeps track of incarceration status, status changes, and criminal case information. This was the most reliable resource to identify whereabouts of participants when they missed follow-up

appointments. This system allowed us to track study participants throughout the study.

Another challenge in relation to following up participants in the prison system includes collection of lab data. This occurred when participants were arrested due to drug diversion or illicit drug use. The routine collection of data from prisoners' medical records was not feasible and time-consuming. This challenge caused missing data for incarcerated participants. Unfortunately, we were not able to overcome this challenge.

Linkage to care

On the STRIDE project, we noticed that many clients demonstrated a negative attitude to the linkage to care when they refused to go through HIV testing and counseling, undertake HAART therapy, or see infectious disease specialists or primary care physicians. One participant with a very low CD4 count, for example, refused to engage with an HIV provider or primary care provider. This could be due to denial, as well as potential stigma and impact on personal relationships.

As a part of the STRIDE project, we also wanted to ensure participants were linked to appropriate care and received comprehensive healthcare services at HUH or at a community hospital for multiple comorbid conditions identified through the screening process. The STRIDE PIs performed an outstanding job in terms of addressing underlying fear and stigma, and they successfully linked project participants to HIV care at the HUH-CIDMAR clinic and to local community providers for continuity of care. The STRIDE projects presented an opportunity to connect District of Columbia clients to needed healthcare services in addition to addiction and HIV treatment.

Addressing Stigma through cultural competency

Minorities with disabilities experience health disparities due to structural barriers associated with demographic differences, race/ethnicity, gender, and LGBT status (Yee, 2011). Stigma leads to discrimination and fear of disclosure. Cultural factors, environmental factors, attitudes, thoughts, and beliefs can translate to high-risk behaviors. We also identified that some participants would refuse enrollment possibly due to HIV/AIDS stigma and disclosure concerns. For instance, some participants refused to complete a psychiatric assessment implemented by a Caucasian study personnel, preferring someone of his or her similar racial/ ethnic background to share personal information comfortably. Additionally, some participants were adamant about bringing pill boxes for medication counts, and wanted monthly supplies of maintenance rather than the weekly supply of medication provided under the study protocol. Both stigma and disclosure had a significant impact on the study, but this issue was well addressed during psychiatric assessment and CBT groups.

In the STRIDE study, ACASI (Audio Computer-Assisted Self-Interview) was administered at baseline and measured the HIV stigma experienced by participants, which was assessed by relying on Sayles and colleagues' (2008) 28-item internalized HIV stigma measure across the four following composite items (score range=0-100): Stereotypes, Disclosure concerns, Social relationships, and Self-acceptance. The STRIDE study identified differences in stigma by gender and sexual orientation. Mean overall stigma score was 39.1 out of 100 (SD=18.0). Females experienced significantly higher overall HIV stigma than males, ($t = -2.0$; $p < .10$) and females had higher

HIV disclosure concerns than males. Homosexuals experienced a higher overall HIV stigma and higher disclosure concerns than heterosexuals.

Understaffing

During this collaboration, we noticed there was an uneven distribution/mismatch in staff hiring and the assignment of responsibilities at collaborative institutes. Although our institute had the majority of clinicians (PIs, residents, social workers), both clinical and research coordination of the entire project at Howard University Hospital was carried out by only one project manager, while collaborative universities hired more than four research staff on average to execute research tasks. Furthermore, some Howard University part time volunteers assisted on various administrative tasks. Overall, project STRIDE provided a great learning opportunity to STRIDE study staff.

Data collection and data sharing

One of the most important tasks of this study was to collect, review, and enter lab data in the database in a timely manner. This task was assigned to Howard University. It is imperative to mention here that initially, collaborative universities were involved with the STRIDE lab data collection. However, due to a system glitch, several elements of data were missing for baseline and quarterly visits. This became an issue, as it was impacting outcome measures of the study. Ultimately, Howard University played a pivotal role in lab data collection from various community providers, where patients were linked to care. This step led to over 90% successful collection of lab data. Furthermore, it was decided that all data analysis would be conducted at collaborative institutes and that

the data would be transferred to collaborative institutes and coded and de-identified for data analysis. We also noticed some hesitation with data sharing from remote collaboration sites. Initiation, involvement, and encouragement for writing project publications were minimal among collaborative institutions.

It was a tedious process to go through concept sheet submissions. There was a time when research staff did not receive any feedback from collaborative universities or received minimal response on research proposals, resulting in less productivity on scholarly activities.

Discussion- Lessons Learned

The overall impact of the collaboration has been extremely positive, although it has been not been without its challenges. The STRIDE team consisted of staff from multicultural and multiethnic backgrounds. Initially, there were some issues in terms of staff collaborative cooperation and differences in opinion. However, eventually the STRIDE team proved to be an excellent team providing excellent quality services to STRIDE participants and setting an example of cultural competency.

Clear and frequent communication among team members has been a key ingredient to ensuring effective and efficient collaboration. Strategies implemented include 1) bi-monthly conference calls 2) annual face-to-face meetings of the full team 3) annual face-to-face meetings of principal investigators, and 5) regular subgroup phone calls. Leadership for this project also faced several basic logistic challenges. For instance, at collaborative institutes, there was an additional challenge of time commitment, as

they often had separate commitments to their own research projects and career development goals. Nevertheless, the STRIDE team demonstrated strong commitment through conference calls and emails.

Collaborative universities organized an intense one week boot camp for research staff and residents. The team was well trained and became acquainted with the various scopes of the project, psychometric scales, clinical interviews, research interviews, the dispensment of detox medications, and the randomization process.

Overall, this collaboration promoted multiple opportunities for professional growth. It provided our residents with learning opportunities to attain research skills while being trained “on the job” as culturally competent scientific researchers. Although HUH residents were the primary workforce for data collection during the study, they were provided minimal additional training and support beyond what was included in the residency curriculum. We identified that there was a pressing need of developing a clinical research program to provide support and guidance to the residents and new investigators. Such a research program should provide residents with an infrastructure, core content on research methodologies, as well as mentor support at collaborative institutes to initiate, complete, and present an independent research project. Additionally, a greater sharing of resources, access to the database, and the involvement of participating site personnel in publications and presentations

would certainly enhance the quality of such collaborations.

Conclusion:

Institutional research collaboration is a valuable tool and greatly benefits and enriches diverse institutions. The basis of such a collaboration should include respect and an understanding of mutual needs. There is usually a power gap in knowledge and resources between the collaborating institutions, and it is important to carefully address these issues at the planning stage. It is very important to maintain open access and facilitate the development of trust during a research collaboration. Some of the pitfalls to look out for are the institutional culture clashes and turf battles. However, if navigated well, inter-institutional collaboration can enable each institution to achieve more together. There is great need for further research to study collaborative models to improve the process of collaboration.

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Conflict of interest

The authors have no actual or potential conflict of interest in relation to this article.

References:

1. Binswanger IA, Stern M, Deyo R, Heagerty P, Cheadle A, Elmore J, et al. 2006. Release from prison—a high risk of death among former inmates. *N Engl J Med*. 2006; 356(2):157–165.
2. Curt G. Beckwith, MD, Nickolas D. Zaller, PhD, Jeannia J. Fu, ScB, Brian T. Montague, DO, MS, MPH, and Josiah D. Rich, MD, MPH Opportunities to Diagnose, Treat, and Prevent HIV in the Criminal Justice System *J Acquir Immune Defic Syndr*. 2010 Dec 1; 55(Suppl 1): S49–S55.
3. Donna K. Ginther¹, Walter T. Schaffer², Race, Ethnicity, and NIH Research Awards *Science* 19 Aug 2011:Vol. 333, Issue 6045, pp. 1015–1019 DOI: 10.1126/science.1196783
4. Guillermo Bernal and Blanca Ortiz-Torres. Barriers to Research and Capacity Building at Hispanic-Serving Institutions: The Case of HIV/AIDS Research at the University of Puerto Rico. *American Journal of Public Health*: April 2009, Vol. 99, No. S1, pp. S60–S65. doi: 10.2105/AJPH.2007.121731
5. Hussain-Gambles et al 2006) M, Atkins K, Leese B. South Asian participation in clinical trials: the views of lay people and health professionals. *Health Policy*. 2006; 77(2):149–165.
6. JT Minor Contemporary HBCUs: Considering institutional capacity and state priorities. A Research Report. East Lansing: College of Education, Michigan State University; 2008
7. Lo B, Garan N. Research with ethnic and minority populations. In: Emanuel EJ, Grady C, Crouch RA, editors. *The Oxford textbook of clinical research ethics*. New York: Oxford University Press; 2008.
8. Mansoor Malik, A Collaboration Between a Historically Black University and an Ivy League Psychiatric Research Center: A Psychiatrist's Reflections of the Impact on Residency Training Culture, Medicine and Psychiatry June 2013, Volume 37, Issue 2, pp 307–313
9. Mary Pat Moeller,¹ J. Bruce Tomblin,² and the OCHL Collaboration³ Afterword: Lessons Learned about Multi-Center Research Collaboration Ear Hear. 2015 Nov-Dec; 36(0 1): 99S–101S.
10. Redwood, S., & Gill, P. S. (2013). Under-representation of minority ethnic groups in research—call for action.
11. Sayles, J.M., Hays, R.D, Sarkisian, C.A., Mahajan, A.P., Spritzer, K., Cunningham, E. (2008). Development and Psychometric Assessment of a Multidimension Measure of Internalized HIV Stigma in a sample of HIV-positive Adults. *AIDS Behavior*, 12(5). 748–758 5.
12. Taylor AL, Ziesche S, Yancy C, et al. Combination of isosorbide dinitrate and hydralazine in blacks with heart failure. *N Engl J Med*. 2004; 351(20):2049–2057. [PubMed]
13. Timothy P. Flanigan, Nanetta Payne, Emma Simmons, Jennifer Hyde, Kaye Sly, and Caron Zlotnick. Lessons Learned From a Training Collaboration Between an Ivy League Institution and a Historically Black University. *American Journal of Public Health*: April 2009, Vol. 99, No. S1, pp. S57–S60. doi: 10.2105/AJPH.2007.122127
14. Wendler D, Kington R, Madans J, et al. Are racial and ethnic minorities less willing to participate in health research? *PLoS Med*. 2005;3(2):e19.
15. Yee, S. (2011). Health and Health Care Disparities among People with Disabilities. Disability Rights & Education Defense Fund. Retrieved 10 Jan 2013 from <http://dredf.org/healthcare/Healthand-Health-Care-Disparities-Among-People-with-Disabilities.pdf>