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The Transformative Role of Authentic Partnership in the Tuskegee Public Health Ethics Program

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Abstract

Partnership is a much-venerated concept and is regularly applied to a broad range of human endeavors, as both a means to an end and the desired end itself. For example, to promote the public's health many programs often rely on partnerships between institutions and communities to implement interventions. Yet despite their generally positive value, partnerships are not without challenges. Unfortunately there are times when a given partnership does not advance a common good, as illustrated by the U.S Public Health Service Syphilis Study at Tuskegee, Alabama (the Syphilis Study), which lasted forty years. However, despite this tragic history, by employing the principles of authentic partnership, the relationships between the federal government, Tuskegee University, and the affected communities are experiencing transformation. By collaboratively working together these partners are able to effectively promote and support ethical public health research and practice.

Keywords

partnership; U.S. Public Health Service syphilis study; Public Health Ethics

Introduction

Partnership is a much-venerated concept and is regularly applied to a broad range of human endeavors, as both a means to an end and the desired end itself. Partnerships are established for a variety of missions and objectives based on the needs or circumstances of individuals or organizations. In the field of public health, for example, partnerships are frequently formed to effectively address challenges to population health.^{1,2,3,4} Indeed when addressing many issues of social justice and equity, partnerships between institutions and communities are often seen as essential.^{5,6} To create partnerships, distinct parties who may posit different objectives, and even different methods, come together to work together to achieve common aims.⁷ However despite their positive value, partnerships are not without challenges.⁸ There are times when a given partnership does not advance a common good. *The U.S Public Health Service Syphilis Study at Tuskegee, Alabama* (the Syphilis Study), which would

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eventually be deemed “ethically unjustified” by a federal investigatory panel,⁹ was in many respects an example of a kind of partnership. The study that involved the U.S Public Health Service (USPHS), Tuskegee Institute (now, Tuskegee University (TU), and even prominent members of the local community, exploited African American men, who were the unwitting subjects of the study, to further the partners own scientific inquiry. The study began in 1932 and ended in 1972, lasting 40 years. Based on sheer sustainability, the Syphilis Study arguably can be counted among the most remarkable of partnerships.

In 1974 the Syphilis Study’s subjects and their survivors won an out-of-court settlement from the federal government that included lifetime medical benefits and burial services.¹⁰ In 1975 the wives, widows, and offspring were added as beneficiaries to the settlement, and the program came to be known as the *Tuskegee Health Benefits Program*. In 1997, the federal government offered an official apology for the Syphilis Study to the study subjects and their families.^{11,12} This occasion ultimately led to the founding of the National Center for Bioethics in Research and Health Care at Tuskegee University (NBC), which seeks to actively address and prevent unethical treatment of persons in research and healthcare settings. Established in 1999, NBC is currently the only center dedicated to the study of public health ethics at a historically black college or university. The goals of the center are to: 1) conduct research, scholarship, and training in public health ethics and bioethics for under-served populations; 2) educate students, faculty, scholars, and the general public about public health ethics issues to improve public health services to under-served populations; 3) promote racial/ethnic and geographic diversity in the field of public health ethics and bioethics; and 4) facilitate effective, respectful, and mutually beneficial community partnerships to address inequities in health and health care and support health promotion for all Americans. Although the *Tuskegee Health Benefits Program* and the bioethics center are closely associated, it is important to note that the two programs are separate. The Centers for Disease Control and Prevention (CDC) through the Division of STD Prevention maintains ongoing support for both efforts.

The Partnership Continuum

Partnerships can be multi-sectorial and inter-sectorial,^{13,14} as is the case between the NBC and CDC. Partnerships can be equitable and self-governing, and at times they can be asymmetrical and bound by rules set by those completely external to the partnership itself, such as the federal laws and regulations that prescribe the use of federal funds. Although such characteristics can influence the reality of any given partnership, they do not necessarily need to fully determine it. The World Health Organization has defined partnership as a “voluntary agreement between two or more partners to work collaboratively toward a set of shared outcomes.”¹⁵ This is a straight-forward definition, and perhaps one that somewhat conceals the more complex and complicating aspects of partnership. Authentic partnership has been defined as a respectful alliance among all parties that values relationship-building, dialogue, and power-sharing.¹⁶ This understanding better gets at some of the challenging intricacies of partnership. For it is indeed the parties who enter into a partnership, how they interact with each other, how they work together towards a common aim, and how they share a vision that determines the nature and consequence of the partnership. It is what can make a partnership effort transformative.^{17,18}

Partnerships are not static—they are dynamic, usually moving in one direction or another, growing in depth and efficacy or dying in stagnation and frustration, or worse. The Syphilis Study, for example, may have begun as well-intentioned but the study lost its way, moving from an outcome of searching for ways to save lives to studying the path to the end of life at the expense of the African American subjects.¹⁹ As the continuum developed by Riggs et al. (Table One) illustrates, the interactions among partners can change based on such things as commitment, the amount and type of change required, the levels of interdependence, power, trust and willingness to share a claimed topic area, territory or turf.²⁰ Authentic partnerships often require extra infusions of resources, beyond money, such as time, and patience, and perhaps the most valuable resource of all—trust. The degree to which the partners are willing to collaborate with each other is fundamentally a function of how much the partners are willing to invest resources in a common enterprise. To be sure, sufficient funds to support a partnership's activities are necessary; however, money alone cannot ensure success. Despite the ongoing investment of funds and labor as the Syphilis Study continued, it became less and less clear what the common enterprise was. If elements such as commitment, trust, power-sharing, including shared decision-making, are in limited supply so too may be the lasting success of a partnership. However, if these elements are abundant among the partners, they can in effect compensate for funding shortages.

In the current partnership between NBC and CDC, the Division of STD Prevention provides funds to the university through a cooperative agreement. The U.S. federal government generally funds external partners through three methods: a grant, a cooperative agreement, or a contract. A cooperative agreement is like a grant but with a very important difference: the significant involvement of the government in the execution of the funded project.²¹ In effect, the cooperative agreement mechanism mandates partnership by requiring that the funded recipient and the federal government work together, each with a substantial role in and responsibility for accomplishing the stated goals of the funded project. However, a funding mandate alone is not likely to guarantee an authentic partnership. Such an outcome is dependent upon the collaboration of the partners. In 2011, CDC and NBC entered into a new cooperative agreement and thus a new partnership. The shared vision and mission of the two entities were—and remains—the advancement of public health ethics in scholarship and practice, thereby building infrastructure that will prevent future exploitation of communities.

Levels of Collaboration in Partnerships

To be effective, partnerships must develop and support collaboration among the partners. In much the same way that a partnership itself can move along a continuum, so too can its levels of collaboration (Table 2).²² As a partnership grows—or dies—the vitality and utility of collaboration among its members can increase or decrease. Member capacity refers to individuals bringing their skills and knowledge to a collaborative effort. The initial collaboration seeds relationships among the partners. These relationships can be influenced by historical and societal context. From the more effective collaborations leaders can emerge. When these leaders are successful they can transform individual interests into a collective force. It is this collective force that ultimately leads to expanded and improved programmatic capacity, which then leads to positive outcomes for all involved.

The Tuskegee Public Health Ethics Program

By 2008 federal programs had entered an era of increased accountability. The federal dollars that were at the time supporting Tuskegee University's commemoration activities were at risk of being withdrawn. The center appeared to be drifting away from the original intent of addressing and preventing unethical treatment of persons in research and healthcare settings; and oversight, monitoring, and guidance was not sufficient to keep the project on track. By 2009 it was clear that a significant reformation of the partnership between CDC and NBC was needed, but there was resistance. As often happens, there was mutual doubt and suspicion. Allocation of resources were affected. Staff were threatened and concerned about their jobs. In the early days of the transition, the partnership, such that it was, was without a common vision or purpose. However, CDC and NBC were able to rebuild the program by adhering to the principles of authentic partnership.²³

The Tuskegee Public Health Ethics Program (TPHP) is the result of this programmatic restructuring. The new partnership between NBC and CDC, demonstrates both the components of the partnership continuum as well as the process of developing effective collaborations. Public Health Ethics has been defined as "a systematic process to clarify, prioritize, and justify possible courses of public health action based on ethical principles, values and beliefs of stakeholders, and scientific and other information."²⁴ Public Health Ethics is a relatively new field as academic disciplines go, although it combines public health and ethics many of the core principles of Public Health Ethics are long-standing.²⁵ Working collaboratively with CDC, NBC developed new goals for the project which now include: 1) providing public health ethics training and practice; 2) promoting partnerships with academic, government, and non-governmental institutions, private sector organizations, and community stakeholders to enhance and advance ethical public health practice; 3) engaging with under-served communities to develop public health services; and 4) advancing public health ethics scholarship in the scientific literature.

In 2010, in conjunction with the Syphilis Study subjects' commemoration event, NBC began conducting an annual *Public Health Ethics Intensive*,²⁶ an initiative funded by CDC. The intensive course focuses on ethical issues across a broad range of public health policies. The following year, NBC partnered closely with CDC's Division of STD Prevention and the agency's Office of Scientific Integrity to launch a Public Health Ethics training program for graduate and undergraduate students with the aim of better preparing these fellows and interns for future ethical professional public health practice. In April 2018, the *Tuskegee Public Health Ethics Program* will mark the 21st anniversary of the study subjects' commemoration and the 7th anniversary of the *Public Health Ethics Intensive*.

June of 2018 will mark the seventh year of the Public Health Ethics fellowships and internships program. To date seventeen Tuskegee University students have participated in the internship component of the program, working with a variety of CDC mentors at the agency in Atlanta, Georgia to complete projects that allow the interns to put the principles of Public Health Ethics into practice. Twelve graduate fellows have successfully completed Public Health projects in some of the most underserved communities in the United States, giving

them important opportunities to ethically perform public health work and improve health equity.

Moreover, the thriving partnership between CDC and NBC has expanded to include CDC's Office of Minority Health and Health Equity, leading to stronger collaboration capacities at both the organizational and programmatic levels. Beginning with the centennial anniversary of National Negro Health Week, CDC and NBC launched a *Public Health Ethics Forum* series. The forums have focused on minority health and women's health; and in 2018 the annual forum will focus on healthy aging. Both the *Public Health Ethics Intensive* and the *Public Health Ethics Forum* series have been featured in the double-blind, peer-reviewed journal, *The Journal of HealthCare, Science and The Humanities*.

Yet among the most important and transformative expansions of the NBC-CDC partnership has been the committed inclusion of the Syphilis Study subjects' family members in the partnership. No longer limited to merely audience participation, subjects' family members now have an active planning and implementation role in the commemoration activities. Additionally, with technical assistance and support from NBC and CDC, in 2014 the family members organized under the name *Voices for Our Fathers Legacy Foundation*. Their unique mission is "to uplift the legacy of the USPHS Study in Macon County by honoring the men in the study and convening their families as a means to preserve history and enrich education in clinical and public health research."²⁷ The foundation recently began awarding academic scholarships and the family members are currently publishing a newsletter entitled, *Voices for Our Fathers*.

Conclusion

Through the years the *U.S. Public Health Service Syphilis Study at Tuskegee* has been used to explain everything from community distrust to intervention ineffectiveness. African American communities, in particular, have frequently been described, sometimes unfairly and inaccurately, as unaccepting and even afraid of various health and social service programs because of what happened to the men who were the subjects of the Syphilis Study.²⁸ In some instances one has but to say the word *Tuskegee* and public health practitioners cringe, perhaps even retreat. Yet there are valuable lessons to be learned from the now infamous and *ethically unjustified* study, but those lessons are only accessible to us if individuals are willing to study them and apply them.²⁹ To enshrine the Syphilis Study in the dusty tombs of shame and regret, or of betrayal and anger, denies the opportunity to use the lessons for transformation.

The successful implementation of the *Tuskegee Public Health Ethics Program* has required committed collaboration among partners who share the mission of advancing ethical public health practice. The past relationships between the parties: Tuskegee University (and NBC), CDC, and the study subjects, their families and their communities, have undoubtedly had their challenges. Terrible mistakes have been made. Grave injustices have been done. Nevertheless, there can be positive change. There can be healing and progress. By "joining-up"³⁰ the Tuskegee University National Center for Bioethics in Research and Health Care, the CDC, and the families and affected communities have been able to forge an authentic

partnership; and together they continue to learn from the instructive lessons of the past and move forward. Working together these partners have been able to more effectively promote Public Health Ethics in research and practice, thereby building a lasting and transformative tribute to the men who were the subjects of the notorious *U.S Public Health Service Syphilis Study at Tuskegee, Alabama*.

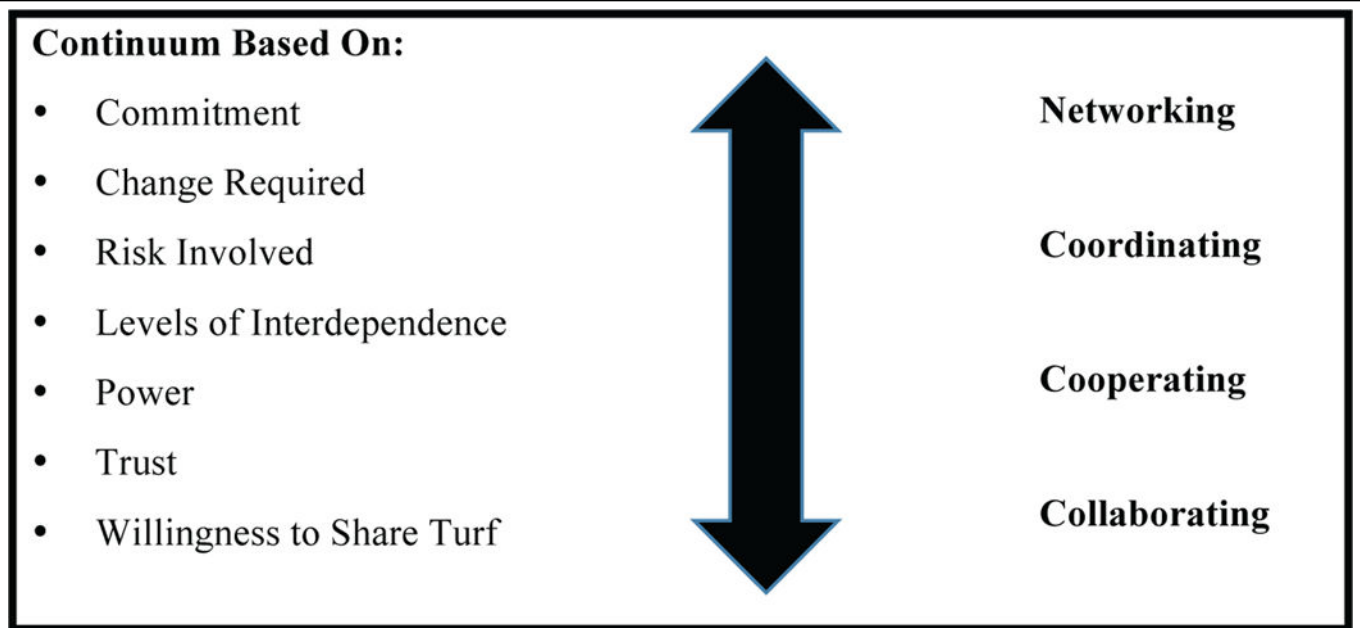
References

1. Baker EA, Wilkerson R and Brennan LK. Identifying the role of community partnerships in creating change to support active living. *Am J Prev Med*. 2012 11;43(5 Suppl 4):S290–9. doi: 10.1016/j.amepre.2012.07.003. [PubMed: 23079261]
2. Roussos ST and Fawcett SB. A review of collaborative partnerships as a strategy for improving health. *Annual Review Public Health*. 2000 21:369–402.
3. Hayes SL, Mann MK, Morgan FM, Kelly MJ, and Weightman AL. Collaboration between local health and local government agencies for health improvement. *Cochrane Database Syst Rev*. 2012 10 17;10:CD007825. doi: 10.1002/14651858.CD007825.pub6.
4. Brizay U, Golob L, Globerman J, Gogolishvili D, Bird M, Rios-Ellis B, and Heidari S. Community-academic partnerships in HIV-related research: a systematic literature review of theory and practice. *Journal of the International AIDS Society*, 18(1), 2015 19354 10.7448/IAS.18.1.19354 [PubMed: 25630823]
5. Wilson S, Campbell D, Dalemarre L, Fraser-Rahim H, and Williams E. A Critical Review of an Authentic and Transformative Environmental Justice and Health Community — University Partnership. *International Journal of Environmental Research and Public Health*, 11(12), 2014 12817–12834. 10.3390/ijerph111212817. [PubMed: 25514142]
6. Gracia JN, and Ruffin J. Partnership, Research, and Leadership to Advance Health Equity and Eliminate Health Disparities. *American Journal of Public Health*, 104(Suppl 4), 2014 S520–S521. 10.2105/AJPH.2014.302201 [PubMed: 25100412]
7. Finch CF, Donaldson A, Gabbe BJ, Muhammad A, Shee AW, Lloyd DG, and Cook J. The evolution of multiagency partnerships for safety over the course of research engagement: experiences from the NoGAPS project. *Injury Prevention*, 22(6), 386–391. (2016). 10.1136/injuryprev-2015-041922 [PubMed: 27016461]
8. Riggs E, Block K, Warr D, Gibbs L. Working better together: new approaches for understanding the value and challenges of organizational partnerships. *Health Promot Int*. 2014 12;29(4):780–93. doi: 10.1093/heapro/dat022. Epub 2013 Apr 28. [PubMed: 23630133]
9. Final Report of the Tuskegee Syphilis Study Ad Hoc Advisory Panel, Department of Health, Education, and Welfare (Washington, D.C.: GPO, 1973).
10. Mays VM. The Legacy of the U. S. Public Health Services Study of Untreated Syphilis in African American Men at Tuskegee on the Affordable Care Act and Health Care Reform Fifteen Years After President Clinton’s Apology. *Ethics & Behavior*, 22(6), 411–418. (2012). 10.1080/10508422.2012.730808. [PubMed: 23630410]
11. Gamble VN. University of Wisconsin School of Medicine, Madison 53706, USA. “Under the shadow of Tuskegee: African Americans and health care.”, *American Journal of Public Health* 87, no. 11 (11 1, 1997): pp. 1773–1778. [PubMed: 9366634]
12. Harter Lynn M., Stephens Ronald J., Japp Phyllis M. (2010) President Clinton’s Apology for the Tuskegee Syphilis Experiment: A Narrative of Remembrance, Redefinition, and Reconciliation, *Howard Journal of Communications*, 11:1, 19–34, DOI: 10.1080/106461700246698
13. Fawcett S, Schultz J, Watson-Thompson J, Fox M, & Bremby R (2010). Building Multisectoral Partnerships for Population Health and Health Equity. *Preventing Chronic Disease*, 7(6), A118. [PubMed: 20950525]
14. Ndumbe-Eyoh S, & Moffatt H (2013). Intersectoral action for health equity: a rapid systematic review. *BMC Public Health*, 13, 1056 10.1186/1471-2458-13-1056 [PubMed: 24209299]
15. WHO partnership definition.

16. Auerbach Susan. Beyond coffee with the principal: toward leadership for authentic school-family partnerships. *Journal of School Leadership*, Vol 20(6) 11 2010.
17. Wilson S, Campbell D, Dalemarre L, Fraser-Rahim H, & Williams E (2014). A Critical Review of an Authentic and Transformative Environmental Justice and Health Community — University Partnership. *International Journal of Environmental Research and Public Health*, 11(12), 12817–12834. 10.3390/ijerph111212817. [PubMed: 25514142]
18. McCullough JM. Successful Academic–Public Health Practice Collaboration: What Works from the Public Health Workforce’s Perspective. *MPH J Public Health Management Practice*, 2015, 21(6 Supp), S121–S129.
19. Mays VM (2012). Research Challenges and Bioethics Responsibilities in the Aftermath of the Presidential Apology to the Survivors of the U. S. Public Health Services Syphilis Study at Tuskegee. *Ethics & Behavior*, 22(6), 10.1080/10508422.2012.730787. 10.1080/10508422.2012.730787
20. Riggs E, Block K, Warr D, and Gibbs L. Working better together: New approaches for understanding the value and challenges of organizational partnerships. *Health Promotion International*, 29(4) 4 2013.
21. Dient-Taillepierre JC, Liburd L, O’Connor A, Valentine J, Bouye K, McCree DH, Chapel T, Hahn R. Toward achieving health equity: Emerging evidence and program practice. *J Public Health Manag Pract*. 2016 Jan-Feb;22 Suppl 1:S43–9. doi: 10.1097/PHH.0000000000000375. [PubMed: 26599028]
22. Kendall E, Muenchberger N, Sunderland MH, and Cowan D. Collaborative Capacity Building in Complex Community-based Health Partnerships: A Model for Translating Knowledge into Action. *Journal of Public Health Management Practice* 18(5), 2012.
23. Murphy JI, Hatfield J, Afsana K, Neufeld V. Making a commitment to ethics in global health research partnerships: a practical tool to support ethical practice. *J Bioeth Inq*. 2015 3;12(1):137–46. doi: 10.1007/s11673-014-9604-6. Epub 2015 Feb 4. [PubMed: 25648123]
24. Centers for Disease Control and Prevention (CDC). 2011 Advancing excellence & integrity of CDC science. *Public health ethics*. <http://www.cdc.gov/od/science/integrity/phethics/>. Accessed 14 Feb 2014.
25. Ortmann LW, Barrett DH, Saenz C, et al. Public Health Ethics: Global Cases, Practice, and Context 2016 4 13 In: Barrett D H, Ortmann L W, Dawson A, et al., editors. *Public Health Ethics: Cases Spanning the Globe* [Internet]. Cham (CH): Springer; 2016. Chapter 1. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK435780/> doi: 10.1007/978-3-319-23847-0_1
26. Warren RC. *Journal of Healthcare, Science and the Humanities*. Volume VII (1). 2017 p 15.
27. Voices for Our Fathers Legacy Foundation. Descendants of the Men in the “United States Public Health Service Tuskegee Study of Untreated Syphilis in the Negro Male 1932–1972”. Lillie Tyson Head, Leadership Team <http://tuskegeebioethics.org/about/voices-for-our-fathers-legacy-foundation/>
28. Katz Ralph V., et al. “Awareness of the Tuskegee Syphilis Study and the US Presidential Apology and Their Influence on Minority Participation in Biomedical Research”, *American Journal of Public Health* 98, no. 6 (6 1, 2008): pp. 1137–1142. [PubMed: 17901437]
29. Mays VM. Research Challenges and Bioethics Responsibilities in the Aftermath of the Presidential Apology to the Survivors of the U.S. Public Health Services Syphilis Study at Tuskegee *Ethics Behav*. 2012 ; 22(6):. doi:10.1080/10508422.2012.730787.
30. Riggs E, Block K, Warr D, and Gibbs L Working better together: New approaches for understanding the value and challenges of organizational partnerships. *Health Promotion International*, 29(4) 4 2013.

Table 1.

Partnership Continuum (as developed by Riggs et al.)



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Table 2.

Levels of Collaborative Capacity (as developed by Kendall et al.)

Member Capacity	Individuals employ a range of skills and knowledge during collaboration
Relational Capacity	Relationships are influenced by the history of interaction and broader social context
Organizational Capacity	Strong effective leadership with facilitation skills transforms individual interests into dynamic collective force
Programmatic Capacity	The ability to guide the design and implementation of program that have impact within the community

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