

Building a Coalition to Overcome Intersecting Stigmas and Improve HIV Prevention, Care Access, and Health Outcomes in New York City

1. SCOPE AND IMPACT

HIV-related stigma, combined with other stigmas, is a critical barrier to accomplishing the goal of ending the HIV Epidemic (EtHE). Stigma interferes with all four key pillars of the EtHE initiative: Diagnose, Treat, Protect, and Respond. Yet stigma reduction has received little attention in the US, especially in comparison to low- and middle-income countries, as demonstrated by the relatively few US stigma interventions included in systematic reviews [1, 2]. Despite all progress made in addressing the HIV epidemic in New York City (NYC) [3], stigma is pervasive and hampers further progress. Stigma in health facilities is particularly egregious, negatively affecting people seeking health services at a time when they are at their most vulnerable [4]. In healthcare settings, the manifestations of stigma are widely documented, ranging from outright denial of care, provision of sub-standard care, physical and verbal abuse, to subtler forms, such as making certain people wait longer or passing their care off to junior colleagues [5-8]. As a result, stigma is a barrier to care for people seeking services for disease prevention, treatment of acute or chronic conditions, or support to maintain a healthy quality of life [9-12]. Stigma seems especially severe for individuals who experience intersectional stigma, defined as “multiple, simultaneous and dynamic interchanges among categories of social difference as it interlinks with power and privilege, and systemic oppression and its operation at the micro, mesa, and macro levels” [13]. In these populations, advances in preventing and treating HIV will be most difficult to accomplish without bringing disparate stigma-reduction efforts together. In addition, we expect that promoting resilience—“an individual’s capacity, combined with families’ and communities’ resources, to overcome serious threats to development and health” (p.66 [14])—will greatly contribute to reducing disparities. The ultimate objective of this grant is to identify where and how stigma-reduction interventions might most optimally be implemented and to explore how the promotion of resilience might contribute to this process. To accomplish this objective, we propose the following three specific aims:

(1) Establish a NYC stigma and resilience coalition (S&RC), a multi-sector, interdisciplinary coalition of HIV-related organizations, affected communities, non-traditional partners, public health officials and academic researchers, to devise strategies for overcoming HIV and related stigmas in communities and healthcare systems and promote resilience among those disenfranchised from available services.

Many institutions in NYC—including community-based organizations, the NYC Department of Health and Mental Hygiene (DOHMH), the New York State Department of Health (NYS DOH), the HRSA-funded Northeast/Caribbean AIDS Education and Training Center (NECA AETC), and research entities—are addressing HIV and stigma. However, these parties are minimally informed about what others are doing, because much of this effort is happening in siloes or as narrowly targeted campaigns. By taking an approach that is transdiagnostic (across health conditions, including substance use and mental health) and intersectional (overlapping social group characteristics, including race/ethnicity, sexual orientation, and gender), this coalition will maximize the population health benefits of addressing stigmas in a more coordinated and efficient manner, and implement and test innovative approaches.

(2) Map and evaluate ongoing activities to reduce HIV-related stigma and promote resilience in healthcare systems and communities with the purpose of assessing the evidence base underlying these activities, characterizing implementation barriers and facilitators, and identifying gaps.

It is unclear whether ongoing stigma-reduction activities are evidence-informed and utilize resilience/strength-based frameworks. It is also unknown what gaps exist in reaching specific communities, sites or geographic areas in critical need of these interventions. Mapping and evaluation of ongoing activities to reduce HIV-related stigma are needed to identify how best to sustain and augment them, including at the policy level, and facilitate implementation activities with wider reach and higher impact.

(3) Identify sites where stigma-reduction and resiliency-promotion interventions are most needed, feasible, and potentially impactful and by whom these interventions could be best implemented, to address the EtHE initiative's four key pillars in NYC.

Information from multiple existing local databases will be integrated to provide insight into the distribution of stigma and its potential drivers in NYC. Awareness of how HIV stigma intersects with other stigmas is growing. We will explore these multiple stigmas to determine which are most salient and for whom; how multiple stigmas can be best addressed simultaneously; and how intersectionality can be incorporated into stigma-reduction activities at organizations providing HIV prevention and/or treatment services.

The proposed project addresses several high NIH HIV/AIDS priorities through their intricate link with stigma: reducing incidence of HIV; improving HIV testing and entry into prevention services; initiation of and retention in treatment; and achieving and maintaining optimal prevention and treatment responses. In addition, the project contributes to a reduction in stigma-related health disparities. Finally, it addresses the medium priority with its focus on HIV-related stigma in the context of other stigmas including those associated with substance use and mental health. Accomplishing the proposed aims will provide a solid basis for the development of an implementation science proposal to more efficiently and effectively reduce HIV-related stigma as a critical barrier to achieving the goal of ending the HIV epidemic.

2 RESEARCH PROJECT PLAN

2.1. Background and Rationale

Addressing HIV stigma is a critical component of a successful strategy to end the HIV epidemic. HIV stigma is the co-occurrence of labeling, stereotyping, separating, status loss, and discrimination within a context of power imbalance that is associated with being diagnosed with HIV [15]. Stigma affects people in its enacted, anticipated, and internalized forms [16]. HIV stigma, in the community and healthcare systems, is a critical barrier to engaging in health behaviors, such as HIV testing and ARV adherence, healthcare-seeking practices, and retention in care [1, 17, 18]. The impact of HIV stigma is exacerbated by other stigmas, including those associated with mental illness, substance use, poverty, race/ethnicity, gender, and sexual orientation [19]. To end the HIV epidemic, stigma needs to be addressed in cross-cutting, sustained, and robust ways. Implementation science has the potential to maximize population health impacts of stigma reduction, but more rigorous research is needed. A global review of stigma implementation science studies found a number of important gaps, as prior studies did not seek to reduce stigma associated with multiple health conditions; did not use conceptual frameworks or validated measures of implementation outcomes; relied on a narrow range of outcomes with sparse descriptions of interventions; rarely addressed stigma at the structural level; and generally only evaluated short-term intervention efforts [20]. Participatory methods and implementation science are important for maximizing successes in reducing HIV-related stigmas.

HIV and related stigma are prevalent in NYC, despite our understanding that they hamper engagement in HIV prevention, treatment, and care [21]. In NYC, HIV stigma reported by people living with HIV (PLWH) remains high, with 79% of PLWH interviewed by the NYC DOHMH saying they had concerns disclosing their HIV status, 58% believing that most people viewed PLWH negatively, 45% having internalized HIV stigma, and 25% reporting they felt they were not as good of a person, felt unclean, or felt that they were a bad person due to having HIV [3]. In a different sample, approximately half of men who have sex with men (MSM) felt that most people in NYC would discriminate against someone with HIV. MSM of color reported this belief at higher levels than did white MSM, and MSM of color had the lowest levels of agreement with the statement that most people in NYC are tolerant of gays and bisexuals [22]. In a recent NECA AETC Delphi survey of 116 panel members with substantive knowledge and expertise in HIV healthcare systems and provider training needs in the NECA region (NY, NJ, PR, USVI), stigma was identified as the third most urgent HIV workforce gap and system capacity issue behind mental health and substance abuse service integration and retention and re-engagement of patients in the care system [23].

To our knowledge, little is being done in terms of stigma reduction that takes intersectionality into account, in part because the evidence base about intersectional stigma is only slowly emerging and little is known about how best to address intersectional stigma [19], although a focus on resilience resources seems promising [14]. Stigmas associated with race/ethnicity, gender, and sexual orientation negatively exacerbate the challenges of many communities in preventing HIV infection or of becoming virally suppressed after diagnosis. In addition, stigma attached to mental illness and substance use complicates HIV stigma due to the high prevalence of behavioral health conditions affecting people at risk for or living with HIV [24-26]. Stigma reduction is not a routine facet of health service delivery or evaluation, nor is it regularly integrated into pre-service and in-service training of all cadres of healthcare workers. An exclusive focus on HIV stigma might not be effective in addressing other stigmas that still hinder progress in ending the HIV epidemic; the proposed coalition represents stakeholders that can elucidate which evidence needs to be generated. The populations in NYC most disproportionately represented in numbers of new HIV diagnoses and whose levels of viral suppression are the lowest are those facing intersectional stigmas, including MSM of color, transgender and cisgender women of color, and individuals of color in their twenties [3]. Different types of stigma share many of the same drivers and manifestations across characteristics and conditions; therefore, taking an intersectional approach to reducing stigma has the potential to increase the impact of investments and effort. A focus on strength-based factors that moderate the relationship between societal stigma and HIV disparities, such as resilience resources, is likely to be an appropriate target for interventions to address societal stigma [14].

Our planning project responds to needs observed in the field. A recent NECA AETC needs assessment uncovered aspects of HIV services and their organization that may reflect stigmatized attitudes, practices, policies, and systems issues that are driving suboptimal care. For example, some agencies have a separate waiting room for HIV clients than for those seeking other medical services; most agencies have policies to protect clients from discrimination around HIV, substance use, and/or mental health issues, but these policies are not consistently enforced; providers know of staff in their agencies who have been reprimanded for not following policies to protect clients living with HIV; providers are willing to take substance use and/or sexual histories but many do not believe that their clients are telling them the truth.

To understand the ways in which stigmas are contributing to disparities in HIV infection and care, in 2017-2018, 50 healthcare organizations participated in a NYS DOH stigma initiative to assess stigma within their sites, the majority of which were located in NYC, and to create stigma-reduction plans. DOH found several areas in need of improvement: 36% of staff said they had not received training on HIV stigma or priority populations most impacted by the HIV epidemic; 26% agreed that HIV infection occurs due to irresponsible behavior; and the populations who experienced the highest levels of stigma were people with a mental health diagnosis, PLWH, and transgender individuals [27]. Submitted stigma-reduction plans suggested that organizations planned to implement policy changes, provider training, and changes to the physical environment of clinics, but it is unknown to what extent these planned activities were carried out, whether they were informed by best practices to address stigma, and if they were evaluated for impact. Therefore, we seek to build on this important initiative that took the first steps to assess and address stigma in a systematic manner by mapping out with these organizations the comprehensiveness of their approaches, the implementation successes and challenges they faced, and to evaluate their greatest points of leverage and impact. Non-clinical HIV organizations were not included in this initiative; therefore, this gap will be addressed by inviting such organizations to participate in the mapping effort.

In addition, through NECA AETC, we have relationships with dozens of NYC agencies, including those funded by Ryan White, as well as federally qualified health centers, from which we can elicit practice and policy information about transdiagnostic and intersectional stigmas to inform our implementation science research project. The other major NECA AETC stigma initiative was launched in 2019 in New Jersey at 20 Ryan White sites that are part of a NJDOH project to integrate behavioral health into HIV care. These sites are in the process of being assessed by a survey adapted from Nyblade [4] to understand transdiagnostic stigma among care providers and how it affects all points along the HIV care continuum. This survey and its psychometric properties

will become part of what the coalition will assess in terms of its utility and applicability to NYC for developing an implementation study that results from this planning project.

The institutions involved in this project are well-positioned to implement the proposed activities and to design impactful follow-up strategies. The proposed project is a collaboration between institutions that are involved in stigma-reduction activities and are aware of stigma-reduction efforts in other institutions. The NYS DOH and the DOHMH Bureau of HIV have prioritized addressing racism, HIV, and other types of stigma in a number of ways, including by addressing racial justice within staff hiring and supervising practices, and by disseminating the Undetectable=Untransmittable (U=U) message to providers and the general public through social marketing campaigns. Two of the DOHMH employees on this project team are leading an effort to address stigma by the HIV Planning Group (HPG), a coalition of providers of HIV prevention and care services in NYC; the NYS DOH's HIV Quality of Care Program engaged clinical sites in employing quality improvement practices to address stigma around HIV, sexual orientation, gender identity and mental health status. In NYC, NECA AETC comprises multiple regional partners based at Weill Cornell Medical Center in Manhattan, Montefiore Medical Center in the Bronx, SUNY Downstate Medical Center in Brooklyn, and Stony Brook University Medical Center, in Queens. Each regional partner conducts needs assessments and is responsive to HIV care providers and healthcare agencies in carrying out training, technical assistance, clinical consultations with providers, practice transformation activities using practice facilitation coaches, and other capacity-building activities. HIV-related stigma continues to receive critical attention throughout the HIV Center's research portfolio.

2.2. Planned Activities. At the start of the project, Project Leadership (PL; see 4.b.3) will draft an operation manual for the project, defining roles, responsibilities, rules of operation, and timeline for the planned activities. They will finalize this in consultation with the Project Team (PT; see 4.b.3). The PT will identify and select members for the S&RC. These members include the PT and representatives from organizations involved in stigma reduction-related activities and from affected communities.

We will utilize RE-AIM to guide our proposed activities. This planning and evaluation framework has often been applied in public health and health behavior change research and is increasingly used in diverse content areas and within clinical and community settings. RE-AIM emphasizes adaptations to programs and expansion of the use of qualitative methods to understand “how” and “why” results come about as well as contextual and explanatory factors related to RE-AIM outcomes [28]. We plan to implement the following activities:

Compendium of Successful Stigma-reduction Approaches. We will compile the evidence for effective stigma-reduction and resilience enhancing strategies with particular attention to interventions from the US. A recent collection of review articles on stigma and global health revealed a paucity of studies from the US (~10%); thus there is a need to find approaches that work in the US context and that are most amenable to adaptation. This review will provide us with a full list of evidence-based stigma strategies from which we can assess whether HIV-related organizations in NYC are using effective approaches. It will guide us in terms of knowing which aspects of interventions are most likely to produce positive and negative impacts. A recent systematic review [4] identified key domains that successful stigma interventions have addressed: policies/procedures/consequences; structure of services; provider preference/comfort; observed stigma (colleagues, staff, leadership); and experienced stigma (self, family member). These will be detailed by the PT and become part of what we explore during Workshops and Town Hall meetings.

Mapping NYC Stigma-reduction Initiatives. This mapping survey will entail the following activities, which will subsequently be implemented. First, we will develop a quantitative and a qualitative mapping tool. The quantitative tool aims to collect information that can be easily pre-coded, whereas the qualitative tool will elicit more contextual and process information. Development of the tools will be informed by evaluability assessment theory [29-34] and RE-AIM [28, 35, 36]. We will also identify the organizations' needs regarding stigma-reduction interventions. The mapping tools will be developed and pretested in collaboration with the S&RC. Second, we

will compile a list of organizations that are known or likely to be involved in HIV and related stigma-reduction activities. Many of these organizations are known because they receive funding through the NYS DOH or the NYC DOHMH. Additional organizations will be identified through the S&RC and through the organizations participating in the mapping procedure. We will develop a database for processing the collected information. We aim to collect information from persons who either designed or implemented the activity. The quantitative tool will be administered via the Internet; organizations will be approached before being invited to participate to increase the chances of completion. To promote completeness and quality of the provided answers, the qualitative tool will be administered in person. We expect to map activities from about 40 institutions. During the implementation of the Mapping Survey, the PL will solicit input from the PT and the S&RC on an ongoing basis.

Consensus Document Regarding Successful Implementation. We will call on the expertise developed by organizations participating in the NYS DOH stigma initiative, where organizations that were most proactive in addressing stigma will be invited to S&RC to highlight lessons learned. Potential topics include how to develop leadership buy-in to address stigma, how to create an organization-wide culture supportive of addressing stigma, and how to routinize stigma reduction within existing core organizational activities.

Mapping of Stigma and Drivers. To explore the distribution of HIV and other stigma, and their potential drivers, we will integrate data from various databases, using numerous available resources to track stigma-related indicators, such as rates of poverty, crime, and HIV, and neighborhood demographics, including race/ethnicity and same-sex households. In addition to census data, these resources include NYC's yearly Community Health Survey; the NYC Community Health Profiles (with indicators regarding education, access to healthcare, etc.); and the Community Health Survey Equity Indicators. This mapping activity will also look at the geographical distribution of stigma-reduction efforts across the city in order to identify areas where populations highly impacted by HIV are not able to access non-stigmatizing services. Moreover, through mapping drivers of stigma in communities in NYC, we will better be able target activities to the communities that need them most.

Engaging Nontraditional Partners. We will identify and engage with nontraditional partners (i.e., persons and organizations not involved in traditional public/research work) to develop messages and approaches for reducing community-level stigma. The information generated in the mapping activities will be valuable in identifying sites most vulnerable to stigma. Nontraditional partners may include local business owners, social organizations, and community leaders working within vulnerable communities in NYC. In addition to helping the study team develop appropriate, meaningful messages to target HIV and other stigmas, the partners will help to identify key stakeholders and platforms (such as social media) to be used in implementing community-level strategies.

Technical Workshops. During the project, we plan to convene four one-day Technical Workshops for which we will invite stigma experts such as Drs. Bruce Link [15, 37-43], Laura Nyblade [44-47], Kristy Stringer [48-51], and/or Janet Turan [17, 19, 52-56]. These Workshops will each have a specific aim, including: (a) exploring the relationship between stigma reduction and resiliency promotion; (b) identifying guidelines to promote quality and impact of stigma-reduction and resiliency-promotion interventions; (c) developing a blueprint for evidence-based interventions addressing intersectional stigma and resiliency; (d) identifying criteria for the selection of opportunities where stigma-reduction and resiliency-promotion interventions are most needed, feasible, and potentially most impactful. Each Workshop will end in a product, which could include a report for discussion in the S&RC, a peer-reviewed paper, or a manual with guidelines.

Town Hall Meetings. The S&RC will host three town hall meetings, engaging the public to give input on how to address intersectional stigma for groups with high numbers of new HIV diagnoses and lower levels of HIV viral suppression, such as MSM of color, transgender women of color, individuals with mental illness or with substance use issues living with HIV. This is also an opportunity to recruit individuals to join the S&RC who are motivated to address stigma, but who may not be connected to already participating organizations.

2.3. Roles of Key Staff. *Project Leadership (PL)* consists of Drs. Theo Sandfort, Cristina Rodriguez-Hart (see biosketch), and Karen McKinnon. The PL guides the conceptualization, design, and implementation of planning grant activities, and will monitor progress at regular intervals. To accomplish this, the PL meets on a weekly basis, and participate in the monthly meetings of the Project Team (PT). Dr. Sandfort supervises the work of the researcher (to be hired) and the HIV Center's postdoctoral fellows. The *Project Team (PT)* consists of Drs. Daria Boccher-Latimore (NECA AETC), Francine Cournos (NECA AETC), Anthony Freeman (NYC DOHMH), Terrance Gardet (NYC DOHMH), Charles Gonzalez (NYS DOH AIDS Institute), Karen McKinnon (NECA AETC), Cristina Rodriguez-Hart (NYC DOHMH), Theo Sandfort (HIV Center), and Patrick Wilson (Mailman School of Public Health). The S&RC meets monthly in the first three project months and then quarterly (in person). For recruitment we will broadly advertise the existence of the S&RC through our networks, including inviting organizations that participated in the DOH stigma initiative and organizations that are members of the HPG. The S&RC will assist in identifying additional organizations and communities to be involved in the mapping activities.

2.4. Expected Project Outcomes. We expect the planned activities to make a critical contribution to ending the HIV epidemic in NYC and to support HIV prevention and treatment in other jurisdictions. While most of the evidence on stigma-reduction interventions comes from isolated studies, the report from the mapping activity will be unique its coverage of stigma-reduction efforts across a large number of clinical and non-clinical organizations within a city with one of the largest HIV epidemics in the US a city frequently held as a model for other US cities in its quest to end the epidemic. The activities of the S&RC will enable the PT to identify ways in which organizations and communities are ready to engage in an implementation science study to reduce stigmas affecting people at risk for or living with HIV. Using the planning process results, we will construct aims and designs for one or multiple implementation science proposals to scale up appropriate stigma-reduction approaches. Moreover, planning process results will enable us to identify and hone implementation methods (e.g., technology, face-to-face); outcomes including access, reach, and retention as they pertain to needed HIV services; and service efficiency and patient outcomes across the HIV care continuum.

2.5. Expected Follow-up Plan. We expect the proposed project to lead to two or more follow-up projects that will contribute to the Program of Ending the HIV Epidemic. One project might focus on addressing stigma within the healthcare setting and the other project might aim at stigma reduction in a specific, marginalized community, for instance Latina transgender women in Queens. All planned activities are focused on identifying these follow-up projects. In and of themselves they will lead to positive outcomes for all parties involved (see 4.b.4). The resulting report will identify underutilized stigma-reduction strategies, populations in need of more stigma mitigation efforts, ways that intersectional stigma is or is not being addressed, and pockets of the city where successful stigma-reduction efforts implemented elsewhere can be applied.

2.6. Impact of Supplement and Follow-up Plan on the Four Pillars of the EtHE. Understanding through the S&RC activities how stigmas interfere with all four key pillars of the EtHE initiative will help identifying gaps in stigma-reduction efforts, and where cross-cutting, multi-level opportunities to reduce intersecting stigmas could be realized. This proposal's transdiagnostic and intersectional perspectives on stigma will optimize population health benefits in HIV testing and case-finding, treatment, prevention, and rapid response to outbreaks. Our mapping of methods and results has a strong likelihood of enhancing coordination between current stigma-reduction activities and those emerging from this process, to promote use of evidence- and resilience-informed strategies that can be adopted and sustained in settings and venues that need them in order to improve their HIV-related services. Finally, the implementation research that results from this planning process will provide knowledge critical to expanding the reach and penetration of HIV testing and PrEP uptake; linkage to and retention in care; medication adherence; and timely responses to potential outbreaks in NYC.

2.7. Monitoring and Evaluating the Ability of the Activities to Achieve the Outcome. Monitoring and evaluating the ability of the planned activities to achieve the proposed outcome is the primary responsibility of the PL, who will monitor progress of all activities in relation to a specific timeline in weekly meetings.

2.8. Mentorship and Collaborations. The proposed project offers several outstanding opportunities for training.

Three current postdoctoral fellows of the HIV Center's training program "Behavioral Sciences in HIV Research" (T32-MH019139; PI: Sandfort), Drs. Brittany Gannon, Bryan Kutner, Jorge Soler, and one fellow from the "Substance Abuse Epidemiology Training Program" (T32-DA031099; PI: Hasin), Dr. Justin Knox, have indicated their commitment to contributing to the project. Dr. Sandfort will mentor their involvement.

The proposed project involves a set of diverse institutions. While bilateral already relationships exist between most of them, it would be the first time that these institutions work together on reducing HIV and related stigma.

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