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Utilizing Creative Arts for HIV Treatment and Prevention Among Black Queer Youth:  
A Scoping Review

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A Scoping Review**

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An abstract of  
A thesis submitted to the faculty of the  
Rollins School of Public Health of Emory University  
in partial fulfillment of the requirements for the degree of  
Master of Public Health  
in Global Health  
2024

## **Abstract**

### **Utilizing Creative Arts for HIV Treatment and Prevention Among Black Queer Youth: A Scoping Review**

By Cody Shymar Henry

The purpose of the following thesis project is to describe current practices of integrating creative art-based interventions as a tool to address HIV treatment and prevention among Black Queer Young People (BQYP) around the globe. Despite advancements in prevention and treatment of HIV, BQYP around the world continue to experience disappointingly high rates of HIV diagnosis and risk of contracting HIV throughout their lifetimes. Utilizing scoping review methodology this review yielded six types of creative art practices implemented across the globe that specifically address HIV treatment and prevention among various social and demographic populations including communities living with and without HIV. The scoping review identified a broad range of art forms that were categorized into groups including theater, poetry, photography, performance, sculpture and visual arts, and music and radio. Theater and theater camp programs can specifically work to promote community dialogue and to reduce HIV and anti-LGBTQ+ stigma. Poetry can promote education and shared learning related to HIV awareness. Photography and specifically the practice of photovoice can help to address both internal and structural related stigma. Participating in performance including Ballroom culture can improve self-expression and promote community dialogue related to HIV health messaging at the community level. The use of sculpture and visual arts allowed for participants to engage in community dialogue regarding HIV and helped to reduce individual and group stigmas related to HIV among women in Uganda. Music and Radio seem to be an acceptable and feasible tool within the HIV prevention and care continuum. Ultimately these art forms can be a specific and targeted approach to addressing high rates of HIV, reducing stigma related to HIV and anti-LGBTQ+, and promoting Pre-Exposure Prophylaxis (PrEP) uptake and awareness among BQYP.

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## **Acknowledgements**

I would like to thank my friends and family who supported me unwearingly and saw the finish line for me, before I could see it for myself.

I would like to thank Dr. Sophia Hussen who was a tremendous inspiration and championing mentor to help me complete my MPH. Sophia, without you I would not have made it to the finish line. Thank you for reminding me why I started this passion project.

Ultimately, I dedicate this work to Black and Brown queer youth who are navigating HIV.

<3

-Cody S. Henry

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## **ABBREVIATIONS & DEFINITIONS**

**ASRHR** - Adolescents Sexual and Reproductive Health

**AYA** - Adolescents and Young Adults with HIV

**ART** - Antiretroviral Therapy

**BQYP** - Black Queer Youth People

**CBPAR** - Community-Based Participatory Action Research

**CDC** - Centers for Disease Control and Prevention

**CDC Youth Definition** - 15-24 years old

**DALY** - Disability Adjusted Life Years

**HIV** - Human Immunodeficiency Virus

**ILO** - International Labour Organization

**LGBTQQ** - Lesbian, Gay, Bisexual, Transgender, Queer, or Questioning

**LGBTQ+** - Lesbian, Gay, Bisexual, Transgender, Intersex, Queer/Questioning, Asexual and other terms (Non-binary and Pansexual)

**MSM** - Men who have sex with men

**MTCT** - Mother-to-Child Transmission

**NCBI** - National Center for Biotechnology Information

**NIH** - National Institute of Health

**PACED** - Process and Collaboration for Empowerment and Discussion

**PLWHA** - People Living with HIV

**PEP** - Post-Exposure Prophylaxis

**PrEP** - Pre-Exposure Prophylaxis

**SDG** - Sustainable Development Goals 2030



**SHOWED** – See, Happening, Our, Why, Educated, Do

**SWP** - The Spoken Word Project

**WHO** - World Health Organization

**WHO Young People Definition** - 10-24 years old

**WHO Youth Definition** - 15-24 years old

**UN** - United Nations

**UNICEF** - United Nations Children's Fund

**UNICEF Adolescents Definition** - 10-19 years old

## **Chapter 1. INTRODUCTION**

Globally, there are over 1.2 billion young people aged 15 to 24 years, accounting for about 16 % of the global population.<sup>1</sup> By 2030, the population of young people aged 15 to 24 years is expected to have grown to 23%, close to a projected 1.3 billion.<sup>1</sup> Currently over 30% of all new HIV infections globally are estimated to occur among youth ages 15- 24 years old.<sup>2</sup> Children who are born with HIV will soon grow into adolescents who must cope with their positive diagnosis.<sup>2</sup> By 2030 1.9 million children and adolescents are projected to be living with HIV.

Although there has been a noticeable downward trend in new diagnosis of the Human Immunodeficiency Virus (HIV) across the board, there are still vulnerable populations at risk of HIV and experience increased difficulties with treatment if they are or become HIV positive. Within specific populations HIV cases are still rising when they should be falling.<sup>3</sup> The World Health Organization (WHO), states a primary factor for worse HIV and AIDS-related outcomes among adolescents is due to a lack of availability of adolescent-friendly services including psychosocial interventions and support.<sup>4</sup> The period of young adulthood calls for intentional prevention and intervention strategies that will impact the current trajectories and ultimately decrease health threats along the adult life course.<sup>5</sup> These intersecting health disparities are felt more greatly among queer adolescents and there is a critical need for more data to develop tailored health interventions for Black Queer Young people (BQYP) specifically.

Globally, in 2021, about 1.71 million adolescents between the ages of 10 – 19 were living with HIV.<sup>6</sup> In 2021, a worldwide estimated 410,000 [confidence bounds: 196,000–650,000] young people between the ages of 10 – 24 were newly diagnosed with HIV, of those 160,000 [46,000–300,000] were adolescents between the ages of 10 and 19.<sup>6</sup> By 2030, 270,000 children

and adolescents are projected to become newly diagnosed with HIV each year.<sup>7</sup> If there are not increased concentrated efforts in interventions for HIV prevention, testing and treatment, 360,000 adolescents are expected to die from AIDS-related diseases between 2018 and 2030.<sup>7</sup> The WHO states that adolescents and young people living with HIV have poorer access to antiretroviral medications, lower adherence to treatment, decreased retention in care, and worse viral suppression.<sup>4</sup>

Young adulthood, spanning ages 10-24, represents a critical period of development characterized by high rates of unmet health needs, disparities in access to appropriate care, poor health status, and high mortality.<sup>5,8</sup> This phase, known as the Youth Decade of Difference, is where young people develop their identities, dispositions, and lifelong aspirations.<sup>8</sup> Intentional health and wellbeing prevention and intervention strategies during this period can significantly impact current health trajectories and decrease health threats as youth transition into adulthood.<sup>5</sup> Adolescence, marked by significant social, emotional, and physical changes, presents numerous challenges. Youth live in a period marked by uncertainty and unique stressors that impact this age group. There is a growing global focus on prioritizing the health and wellbeing of adolescents, particularly in areas such as HIV, sexual reproductive health, mental health, injury, and non-communicable diseases.<sup>9</sup> Prioritizing adolescent health and healing from a preventative perspective can ultimately contribute to achieving the aims of the Sustainable Development Goals.<sup>9</sup>

While contextual experiences of Blackness and health status are different based on country of study, Black populations around the globe continue to suffer poor health outcomes. In Sub-Saharan Africa, for example, HIV remains the number one cause of disability-adjusted life years (DALYs) lost for both males and females, and among both younger (10- 14 years) and

older (15- 19 years) adolescents.<sup>10</sup> Adolescents living in Sub-Saharan Africa experienced the most severe impact of HIV/AIDS compared to adolescents in any other region of the world.<sup>10</sup> Around the world global anti-Black racism contributes to decreased health status among Black youth. Black youth around the globe experience decreased mental health outcomes and higher rates of suicide due to experiences of violence, racism, and poverty.<sup>11</sup> Stressors among Black youth are even more exacerbated if they happen to identify as Black and LGBTQ+.<sup>11</sup>

At the epicenter of these intersecting identities and socio-economic barriers are Black queer young people (BQYP) who are navigating HIV treatment and prevention alongside everyday stressors associated with living in an anti-Black world. Black queer youth including those who identify as same gender loving, transgender, gender non-conforming, and gender nonbinary,-experience compounding effects of several intersecting identities that impact their life course trajectories.<sup>4,6,7</sup> These daily stressors such as violence, poverty, racism, HIV stigma, class difference, structural racism, and homophobia have led (BQYP) to experience higher rates of HIV diagnosis and increased risk of developing HIV over the course of their lifetimes.<sup>4,6,7</sup>

Two thirds of Black transgender woman are living with HIV according to a 2020 CDC report on HIV infection, prevention and testing behaviors among transgender women living within seven different US cities.<sup>12</sup> Only 32% of HIV negative transgender woman reported using PrEP to prevent acquiring HIV.<sup>12</sup> Among young Black men who have sex with men (MSM), HIV-related stigma is associated with sexual risk behaviors, hesitation and reluctance to obtain HIV testing or care, lower adherence to treatment medications, and non-disclosure of disclose positive HIV status.<sup>13</sup> Historic disparities caused by the intersections of gender, sexuality, and racism uniquely impact treatment and prevention of HIV/AIDS among (BQYP) ages 10 - 24.

Black Queer Young people need to be provided with tailored coping mechanisms and tools on how to navigate HIV treatment and prevention.<sup>5</sup>

Creative arts can serve as a nontraditional and non-medicalized approach to navigating HIV among queer Black communities and serve as an intentional tool in stigma reduction. The current HIV care continuum can be strengthened if creative art based tools are implemented into clinical care and social support for BYQP<sup>14</sup>. Art was utilized as a methodology to raise social consciousness in popular culture and raise awareness of the neglected HIV/AIDS crisis across the United States dating back to the early 1980s.<sup>15</sup> As art and protest emerged to combat HIV/AIDS-related health discrimination, Black queer people were historically left out, for the most part, of the presence LGBTQ+ people had in public media representation, and the art space was mostly occupied by white people. This lack of voice and representation in community dialogue left Black people invisible and vulnerable as HIV/AIDS silently ravished their communities. Creative arts can be used to engage youth in practices to inform policy surrounding HIV/AIDS at the same time building their self-efficacy to navigate and prevent HIV in their own communities.<sup>16</sup> Preliminary case control studies show that creative arts-based interventions can help improve HIV treatment and prevention of HIV among individuals at risk and living with HIV.<sup>17</sup>

There is a need to establish credible empirical evidence for the potential benefits of integrating creative art practices into the established HIV treatment and prevention care continuum model for youth demographics. If current trends continue there will be an estimated 183,000 new annual HIV infections among adolescents by 2030.<sup>6</sup> The purpose of the following thesis project is to contribute to existing literature by conducting a systematic scoping review of current examples of creative art-based interventions implemented as a tool to address HIV

treatment and prevention among BQYP. This scoping review seeks to understand the extent to which creative arts-based approaches are effective in addressing HIV treatment and prevention among BQYP and to assess the relevance of these strategies within the targeted communities of BQYP.

## **Chapter 2. LITERATURE REVIEW**

### **Youth Health and HIV**

Over the last decade there have been a growing number of publications that contribute knowledge to help understand the high-risk health status profile of young people in the United States.<sup>5</sup> The collection of publications identifies that young adults between the ages of 18- 25 experience higher rates of mortality, unplanned pregnancy, and also experience a lower access to healthcare compared to those immediately younger and those immediately older.<sup>18-26</sup>

Biologically, there is increasing evidence that our human brains are not fully developed until mid to late 20's, specifically, the communication and interconnectedness of the emotional and motor prefrontal cortex is almost, but not quite, complete growing during young adulthood.<sup>27-29</sup>

Overall, there is no clear definition or guideline for what is considered a young person. The Society for Adolescent Health and Medicine conducted a poll of its national and international listserv members, representative of over 10 countries, and found that 'youth' and 'young people' are terms that have been use interchangeable across literature and research.<sup>5,30</sup> Additionally, there is no clear designations of youth demographic data collections systems for, health promotion, research practice, and policy development at the international nor national level, further contributing to a lack of cohesion across the field of adolescent health and medicine.<sup>5</sup> There is a need for clear distinction and age range definition for the developmental

and social stages of young adulthood.<sup>5</sup> WHO's definition of "young people" includes youth and young people ages 10 to 24.<sup>31</sup> The United Nations (UN) define youth as 15- 24 years of age.<sup>1</sup>

Globally, in 2016 there were 250 million *more* adolescents aged 10- 19 who lived in countries categorized by multiple health burdens than recorded in 1990.<sup>10</sup> Adolescents living in these countries face compounding health burdens; putting them at increased risk of suffering decreased health status caused by both communicable and noncommunicable diseases, poor nutrition, as well as sexual and reproductive health issues. From 1994 to 2017, AIDS-related deaths totaled an estimated 773,000 among adolescents 10- 19 years old.<sup>32</sup> In 1994, HIV/AIDS accounted for less than a single percentage point (0.2%) of DALYs among adolescents aged 10- 14, however, by 2017 HIV/AIDS accounted for 7% of DALYs in the 10-14-year old age group. Among older adolescents age 15-19, HIV/AIDS increased from 1% of DALYs in 1994 to 6.8% by 2017.<sup>32</sup> Across the globe, when accounting for new infections, and improved access to and availability of ART treatment for PLWH, the number of 10-19-year-olds living with HIV increased from approximately 920,000, in 1994, to 1.6 million in 2018.<sup>33</sup> In the United States, in 2019, for every 100 people diagnosed with HIV aged 13 to 24, 80 received some care, 59 were retained in care, and 63 were virally suppressed.<sup>34</sup> In 2019 the CDC noted, 24% of all PLWH in the United States missed at least 1 HIV medical care appointment over the past 12 months. The group with the highest rates of missed HIV medical care appointments over the past 12 months were young PLWH 18-24 years old. 38% of all 18-24 year old PLWH missed at least one appointment within the past 12 months.<sup>34</sup>

Of all adolescents between the ages of 10-19, who are living with HIV, 1.47 million (86%) are living in Sub-Saharan Africa.<sup>6</sup> Each week, about 4,900 young women aged 15-24 become HIV positive across the world.<sup>35</sup> When compared to boys and young men, girls and

young women are twice as likely to be living with HIV in Sub-Saharan Africa.<sup>35</sup> In total girls and young women accounted for 63% of all new HIV infections across Sub-Saharan Africa, in 2021.<sup>35</sup> 25% of adolescent girls and 17% of adolescent boys aged 15-19 in Eastern and South Africa have been tested for HIV in the past 12 months.<sup>6</sup> (testing rates in Western Central)

In 2018, more than half of all new HIV infections occurred among key vulnerable populations and their sexual partners including young MSM, transgender persons, young sex workers and their clients, and young people who inject drugs and young prisoners.<sup>36</sup>

Around the globe higher rates of poverty correlate with increased HIV diagnoses.<sup>37</sup> Young people are disproportionately affected by unexpected economic hardship, lack of job opportunities, and structurally weak labor markets. When compared with persons <sup>3</sup>25 years, young persons aged 15- 24 years of age are approximately three times more likely to be unemployed.<sup>38</sup> Youth with HIV are the least likely to be aware of their status or to have achieved a suppressed HIV viral load.<sup>39</sup> In 2014, Public health officials uncovered noted associations between HIV-related stigma and decreased use of voluntary counseling, decreased HIV test screenings, less willingness to disclose HIV test results, and lack of correct knowledge about transmission of HIV.<sup>40</sup> General stigma and HIV-related stigma is a large barrier in HIV treatment and prevention.<sup>41</sup>

Growing public health data highlights structural racism as a critical mediator of health injustice and a key social determinant of population health.<sup>42-44</sup> Health inequities refer to systematic disparities in the opportunities and access various social and demographic groups have the pursuit of optimal health that result in unjust and preventable differences in health outcomes.<sup>42</sup> Structural racism results in decreased health status and DALYs among Black and other racialized minorities across multiple health indicators.<sup>45</sup>



## **Black Communities and HIV**

According to the *2020 United States Census*, the Black or African-American population alone currently represent 12.4% population (41.1 million) of all people living in the United States.<sup>46</sup> Of those people living with HIV, 479,300 were Black/ African American.<sup>47</sup> In 2019 alone, Black/African-American adults and adolescents aged 13 and older accounted for 42% (36,801) of new HIV diagnoses in the United States and surrounding territories.<sup>47</sup> As reported by the CDC, among Black/African-American people, most new cases of HIV diagnoses in 2019 were among Black/African-American men (cisgender and transgender men). Within the total 11,493 subpopulation of Black/African-American men newly diagnosed with HIV 79% (9,123) of diagnosis involved male to male sexual contact.<sup>47</sup>

Progress has been made with an 8% decrease in HIV diagnoses among Black/African-American people overall from 2015 to 2019.<sup>47</sup> However, over 60 years after the first diagnosed case of HIV/AIDS in the US, Black MSM are still expected to have a 50% chance of developing HIV over the course of their lifetimes.<sup>48</sup> In 2019, for every 100 Black/African-American person with diagnosed HIV: 74 received some HIV care, 56 were retained in care, and 61 were virally suppressed.<sup>47</sup> As of 2021 MSM have a 28 times greater risk of acquiring HIV compared to people of the same age range and gender.<sup>3</sup> Transgender women have a 14 times higher risk of acquiring HIV than adult cisgender women.<sup>35</sup> Across the board, Black American communities experience lower rates of viral suppression when compared to all people diagnosed with HIV.<sup>47</sup>

## **HIV Treatment & Prevention: A Global Perspective**

Since the early 1980s, the HIV/AIDS epidemic has challenged public health officials, medical providers, and those affected by HIV to respond. The signs and symptoms of HIV vary depending on the stage of infection. HIV attacks the human body's natural defense against

infections and cancers by weakening the immune system. Using data from 1990- present, UNAIDS estimated that 84.2 million [64.0 million–113.0 million] people have become infected with HIV. It is estimated that a total of 40.1 million [33.6 million–48.6million] people have died from AIDS-related illnesses since the start of the epidemic. As of 2021 there is an estimated 38.4 million [33.9 million–43.8 million] people globally living with HIV.<sup>35</sup> There is still a need to prevent the spread and transmission of HIV considering the 1.5 million [1.1 million–2.0 million] people who became newly infected with HIV in 2021.<sup>34</sup> HIV can be transmitted via a variety of body fluids, including blood, breast milk, vaginal secretions, and semen. HIV can also be transmitted from a mother to her child (MTCT) during pregnancy and delivery.<sup>49</sup> An estimate of 650,000 [510,000–860,000] people died from AIDS-related illnesses in 2021. In 2021, 28.7 million people were estimated to access antiretroviral therapy for HIV treatment.<sup>35</sup>

HIV/AIDS treatment and prevention has traditionally relied on an established medical approach to the disease. WHO recommends HIV testing and counseling as a way to identify individuals who are HIV positive and unaware of their status.<sup>49</sup> If an individual is identified as HIV positive, they are recommended to start Antiretroviral Therapy (ART), which is prescribed by a healthcare provider as a treatment to reduce the amount of HIV virus in the blood. There is no cure for HIV/AIDS yet, but if an individual adheres to their treatment regimen (ART) as prescribed, HIV can be controlled at a manageable level.<sup>49</sup>

Immune function of the body is measured by CD4 cell count. The most advanced stage of HIV infection is acquired immunodeficiency syndrome (AIDS). A person with HIV is considered to have progressed to AIDS when: their number of CD4 cells falls below 200 cells per cubic millimeter of blood (200 cells/mm<sup>3</sup>).<sup>50</sup> Care providers use HIV viral load blood tests to measure the amount of HIV present in the blood of someone who is diagnosed with HIV.<sup>51</sup> Viral

failure can indicate a lack of adherence to ART or a need to try a new HIV treatment regimen due to possible resistance to current medication.<sup>51,52</sup> With adequate adherence to ARTs, within six months of diagnosis a person living with HIV (PLWH), can eventually reach HIV viral suppression. Viral suppression is achieved when an individual diagnosed with HIV has a viral load that is so low, it cannot be detected by molecular or nucleic acid amplification tests.<sup>51</sup> Viral suppression is determined or ‘achieved’ when a person living with HIV has less than 200 copies of HIV per milliliter of blood.<sup>34</sup> Despite varying markers that exists for determining HIV viral load, the cutoff value of <200 copies/mL (virally suppressed) was based on the following definition of viral failure: viral load of  $\geq 200$  copies/mL (not virally suppressed).<sup>53</sup> This threshold of “undetectable” HIV status, [ $< 200$  copies/mL is often chosen as standard measure for comparability across studies and different settings], was shown to be sufficient to avoid HIV transmission.<sup>54</sup>

In recent years a large body of clinical evidence confirmed that if a person adheres to ART as prescribed and achieves viral suppression or undetectable status, HIV cannot be sexually transmitted to another person.<sup>55</sup> Effectively this concept is commonly known as HIV Undetectable = Untransmutable (U=U) or Treatment as Prevention (TasP). Treatment for HIV is a critical resource in preventing the sexual transmission of HIV.<sup>56</sup>

In addition to treatment as prevention (TasP), the WHO recommends condom use, Pre-exposure Prophylaxis (PrEP), Post-exposure Prophylaxis (PEP), sexual partner reduction, and/or limiting risk-behaviors all as effective mechanisms for preventing sexual transmission of HIV.<sup>49</sup> PEP is a short-term course of ART medication that can be taken within three days after a potential exposure to HIV occurs.<sup>57</sup> PrEP is a daily medication that can be taken to prevent

HIV.<sup>58</sup> These combined efforts of HIV treatment and prevention are known as the continuum of HIV care.<sup>59</sup>

In the United States, the *National HIV/AIDS Strategy* introduced a large scale medicalized approach to HIV in 2010-2015 and according to current standards of care it was effective at testing and treatment, however, there is a call for a more modernized strategy within the HIV care continuum.<sup>60</sup> The US National HIV/AIDS Strategy (2010- 2021) emphasized the need for additional resources focused on populations that were most impacted and most vulnerable to HIV, however, this approach primarily focused on testing, linkage to care, and treatment as prevention.<sup>60</sup> UNAIDS “95-95-95” goal states that 95% of the people who are living with HIV are aware of their HIV status, 95% of the people who know their HIV status are on ART medications, and 95% of the people on ARTs are virally suppressed.<sup>61</sup> The “95-95-95” goal also states that annually 200,000 new HIV infections or fewer and zero HIV discrimination by 2030.<sup>61</sup> Utilizing relevant data from 2010, CDC implemented the National HIV/AIDS strategy through 2020. The strategy was enacted with the following strategic goals: (1) Reduce new infections, (2) Increase access to care and improve health outcomes for people living with HIV/AIDS (PLWHA), (3) Reduce HIV-related health disparities and health inequities, and (4) Achieve a more coordinated national response to the HIV epidemic.<sup>60</sup> While these strategies are effective, overall approaches to HIV treatment and prevention that are focused solely on medication adherence, testing, and risk-related behavioral factors fail to consider the social determinates of health that impact people living with HIV/AIDS and the populations who are most at risk of contracting the virus. Social determinants of health have been identified as the main driver of why public health officials continue to see higher rates of HIV over the past 60 years among vulnerable populations.<sup>62</sup>

From 1994 to present day, Sub-Saharan Africa has experienced the greatest burden of death and disability caused by HIV than any other region across the globe.<sup>10</sup> In Sub-Saharan Africa, HIV remains the number one cause of DALYs lost for both males and females, and for both younger (10- 14 years) and older (15- 19 years) adolescents.<sup>10</sup> Adolescents living in Sub-Saharan Africa experienced the most severe impact of HIV/AIDS compared to adolescents in any other region of the world.<sup>10</sup>

### **Creative arts-based interventions in Health and Healing**

Since the start of the HIV/AIDS crisis, the arts and media played a critical role in helping to create a call to action for the US government to address the spiraling HIV epidemic. Creative arts have been historically used as a tool of protest, social advocacy, and a way to call to action against human injustice. For artists living in the 1980s and 90s, the AIDS epidemic was a defining moment.<sup>63</sup> Art was utilized as a methodology to raise social consciousness in popular culture and raise awareness of the neglected HIV/AIDS crisis across the United States dating back to the early 1980s.<sup>15</sup> Creative art produced by artists who experience HIV and AIDS firsthand began to emerge and push against the persistent stigmatization of the LGBT community. The art itself represented political activism.<sup>63</sup>

However, as art and protest emerged to combat HIV/AIDS health discrimination, Black queer people were historically left out of the presence queer people had in public media representation, and art spaces were mostly occupied by white people. This left Black people invisible as HIV/AIDS silently ravished their communities. Black youth have drastically higher rates of HIV across the board when compared to their counterparts. Creative arts can be used to engage youth in practices to inform policy surrounding HIV/AIDS, at the same time, building their self-efficacy to navigate and prevent HIV in their own communities.

## **Creative Art as Therapy**

In support of these theories, the arts have been found to foster prosocial behavior, a shared sense of success, physical coordination, shared attention, shared motivation, and group identity. Relatedly, the arts have been shown to help build social cohesion and support conflict resolution through developing cognitive, emotional and social skills for constructive engagement with conflict, and by supporting empathy, trust, social engagement, collaboration, and transformative learning, thereby producing more cooperative relationships.<sup>65</sup> There is support for the use of art in clinical healthcare settings. According to a group of surveyed mental health professionals there is a consensus that creative arts can be useful in helping to treat depression among adolescents.<sup>66</sup> The use of arts and creative engagement to: reduce suffering, promote health, and assist healthcare organizations in providing effective patient-centered care.<sup>67</sup>

There is no separation between the human experience and creativity. When making art we are also grappling with our history, our heritage, our politics, and the way we learn.<sup>68</sup> The survey, *What Americans Say About the Arts in 2018*, conducted by Ipsos on behalf of Americans for the Arts, is the second in a series of national public opinion surveys which seeks to gauge the public perspective on: (1) personal engagement in the arts as audience and creator, (2) support for the arts education and government arts funding, (3) opinions on the personal and well-being benefits that come from engaging in the arts, and (4) how those personal beliefs extend to the community.<sup>69</sup> To ensure precision and generality of the findings, a nationally representative sample of 3,023 adults were interviewed online (n= 3,023).<sup>69</sup> The accuracy of Ipsos online polls has a credibility interval of  $\pm 2.0$  percentage points.<sup>69,70</sup> 73% of Americans surveyed are in favor of the government providing funding for arts in healthcare programs.<sup>71</sup> Creative art has the ability to make something real and or visible. 81% believe the Arts are a “positive experience in a troubled world.”<sup>69</sup> 73% believe the Arts give them “pure pleasure to experience and participate

in.”<sup>69</sup> 72% believe “the Arts unify our communities regardless of age, race, and ethnicity.”<sup>69</sup> 73% feel the Arts “help me understand other cultures better.”<sup>69</sup>

### **Arts Education and Creative Youth Development**

Across the world, communities are working to achieve a higher vision of access to quality arts education for young people irrespective of socioeconomic status and cultural background, and are utilizing multi-pronged approaches that encompass school-based arts education, arts integration across subject matter, and out-of-school time arts.<sup>72</sup> The recently coined term, *Creative Youth Development (CYD)* emerged from the first National Summit on Creative Youth Development held in Boston Mass, March of 2014.<sup>72</sup> *Creative Youth Development (CYD)* is a ‘theory of practice that integrates creative skill building, inquiry, and expression with positive youth development principles, fueling young people’s imaginations and building critical learning and life skills.’<sup>73</sup>

The first, National Summit on Creative Youth Development, which served as a key milestone in the evolution of creative youth development in the United States, and was organized by the Massachusetts Cultural Council, National Guild for Community Arts Education, and Presidents Committee on the Arts and the Humanities.<sup>72</sup> New policy and advocacy recommendations emerging from the Summit, marked an important appreciation and meaningful advancement for implementing CYD into standardized practice.<sup>72</sup> The formative summit gave rise to heightened focus and new energy surrounding creative youth development.<sup>72</sup> Creative Youth Development started in 1889 with grassroots beginning has now grown into an empirically supported field.<sup>72</sup> Today CYD, programs are associated with setting high expectations for youth and encouraging them to contribute meaningfully in local community efforts geared toward social justice.<sup>73</sup> CYD is a social justice approach. “At risk” is a term that is not typically used in CYD due to the nature of possible stigmatizing language.<sup>72</sup> The City of Seattle Office of Arts and Culture and Culture

organized a forum dedicated to CYD in 2015.<sup>72</sup> The field of CYD is becoming more formalized and structured. Newly developed CYD programs enact refined youth leadership structures with defined opportunities for youth to assume increased levels of influence and visibility.<sup>72</sup> CYD provides community connection to community and social landscapes.<sup>72</sup> In 2014, Colorado-based creative youth development organizations Formed the Alliance for creative Youth Development and launched a website at <https://www.creativeyouthdevelopment.org/peer-networks/>.<sup>72</sup> Youth are empowered through increased implementation of CYD programs. Young people are a resource and not a problem.<sup>74</sup> Young people are having the opportunity to share their experiences and speak up for themselves while shaping policy for CYD programs as members of advisory boards, as participants in community forums, and as advocated before bodies of elected officials.<sup>72</sup>

### **Chapter 3. METHODS**

I adopted arts-based scoping review methodology from Bunn *et al.* who utilized traditional scoping review methodology as define by Arksey and O'Malley and Levac *et al.*<sup>75-78</sup> Arts-based health promotion typically includes collaboration and partnerships between researchers and practitioners across the arts, social sciences, and biomedicine fields.<sup>76</sup> A scoping review methodology allows for interactive and exploratory approach to knowledge gathering and synthesis. Specifically, I followed the five stages proposed by Arksey and O'Malley of 1) identifying the research question, 2) identifying relevant studies, 3) study selection, 4) charting the data, and 5) collecting, summarizing, and reporting results.

Unlike systematic reviews, a scoping review does not seek to answer narrow questions with the best available evidence, but instead aims to map out what is known about a topic, identifying gaps in research and informing future investigations.<sup>78</sup>



## **Identifying the research question**

Although art therapy and creative arts-based approaches to HIV and health promotion have been widely used, there has not, to my knowledge, been an encompassing review of these creative arts-based approaches among diverse populations and vulnerable groups. Specifically, arts-based approaches to HIV treatment and prevention have not adequately been assessed for Black Queer communities and adolescent groups. To address this gap, I sought to answer two broad questions: (1) How effective can creative arts-based approaches be for HIV treatment and prevention among Black queer youth populations, and (2) How relevant are these strategies can be among the target communities of BQYP. In the following review, I provide nuance to this question by synthesizing global creative arts-based approaches to HIV treatment and prevention. Secondly, I seek to explore the benefits and challenges that the existing literature reports related to creative arts and HIV treatment and prevention to produce a synthesis of the learning points from the corpus.

## **Identifying relevant studies**

Arts-based health promotion in HIV treatment and prevention typically involves numerous collaborators and relies on research and practitioners from diverse disciplines including artists, social scientists, and biomedical researchers. For this reason, I searched a variety of databases representative of the plurality of disciplines in the scope of this review. Preliminary searches were done on PUBMED, Web of Science, and Emory Library platforms. To capture as many relevant citations as possible, a wide variety of medical, psychological, behavioral, and public health databases were searched to identify, primary, secondary, and tertiary data sources relevant to creative art and HIV among the study population utilized for this review. The searches were limited to papers published in English and included papers from a global perspective. The search was not bound to specific regional locations. Bibliographies from

the included papers were searched for results that were not identified in the database searches. During preliminary searches, I found that social media, online, and gamified app approaches to HIV treatment and prevention emerged when searching for arts-based approaches. I decided not to include these approaches in the review.

### **Study selection**

Titles were screened for records that appeared to represent efforts to include artistic practices in the HIV treatment and prevention care continuum. During secondary screenings, abstracts and full-text articles were assessed for relevance, applying the following inclusion criteria: studies published from the 1980s to the present day, including both secondary and primary studies; global publications written in English; studies focusing on clinical, behavioral, and psychological approaches to HIV for the study population, including Black men, Black women, and Black youth; articles addressing the study population living with or at risk of HIV; and studies examining public health models that integrate creative arts in HIV treatment and prevention.

### **Data Sources**

Data sources utilized in this scoping review included searches of PubMed, Web of Science, and the Emory University Library database. Additionally, information was gathered from the CDC, the WHO, the UN, various archives, news sources, and general information found on the web.

### **Charting the data**

Given the interdisciplinary nature of the inquiry at hand and the multiple disciplines from which the records were gathered, I used a template that was broad enough to encompass approaches that did not fit the traditional ‘headings’ of biomedical/public health enquiry. In this scoping review, the template for organizing data included the following fields: author(s), year of publication, study location, and study duration; study community or target group; aims of the

study or paper; art forms used or discussed; methodology or approach; activities or interventions; analysis, undertakings, or outcome measures; and study results, key arguments, and key messages I worked to maintain a uniform approach to data charting, however, due to the interdisciplinary nature of the literature some information was not available for all records.

### **Collecting summarizing and reporting results**

The content generated during the charting process was combined into an Excel database, which was used to generate descriptive statistics relating to the art form used or discussed and the target population/ study community. Graphs and visualizations were produced at this stage to aid in interpreting the data. After consideration of the potential approaches to summarizing the data, I decided to organize the results by art forms utilized in the approaches/interventions. This allowed for the broadest inclusion for reporting. During the process of summarizing the data I maintained these groupings.

## **Chapter 4. RESULTS**

### **Scoping review search and initial screening**

Electronic web-based searches were conducted to identify materials dating back to the 1980s, at the onset of the HIV/AIDS crisis. This yielded 464 possibly relevant citations (**Error! Reference source not found.**, Figure ). The potential relevance of each citation was evaluated utilizing the selection criteria. Titles were screened for records that appeared to represent efforts to include artistic practices in the HIV treatment and prevention care continuum. In secondary screenings abstracts and content was screened for relevance and final selection, using the inclusion criteria defined above.

Utilizing the established inclusion and exclusion criteria, 18 citations were included in the final review (**Error! Reference source not found.**). Data bases were last searched March 31,

2023. After studies were selected, they were evaluated for their relevance to study population and their impact on the HIV treatment and prevention care continuum.

### **Description of papers included**

This review identified work representing eight different countries (Figure ). Of the 18 included studies, 10 (48%) took place in the United States of America, three (14%) were conducted in the United Kingdom, two (9%) took place in South Africa, and two (9%) were conducted in Uganda. The remaining countries (20%) were only associated with one study (Canada, Eswatini, Ghana, and Mozambique). Types of research study and projects included: formative research, quasi-experimental, randomized controlled trials (RCT).

The included studies addressed HIV treatment and prevention at both individual and community levels, encompassing study populations ranging from middle school-aged to elderly individuals (Figure 4). The target study groups represented in these studies were diverse and included adolescents with HIV (contracted perinatally), Black MSM with experience using PrEP, the Black queer ballroom community, Black MSM with HIV, people living with HIV/AIDS, public health officials, the general public, LGBTQ+ teens (aged 13–18 years), underserved youth populations, at-risk high school-aged youth, women affected by HIV, young people, and the entire community (Figure 4).

The studies employ a total of six different creative forms of art for HIV/AIDS treatment and prevention (Figure ). The six different creative art forms implemented among participants represent artistic practices in theatre (28%), Photovoice (28%), music (17%), performance (11%), poetry (11%), and visual art (5%). The included papers highlight a range of target groups including youth living with HIV/AIDS, Black MSM, and Black MSM who are using PrEP (Figure ).

### ***Photovoice***

Five (28%) papers utilized photovoice for HIV treatment and prevention.<sup>79-83</sup> Photovoice is a participatory “process by which people can identify, represent and enhance their community through a specific Photograph technique.” Photovoice is a method that utilizes images as a tool to deconstruct social and health problems by posing meaningful questions to participants in a community to find actionable solutions.<sup>84</sup> In these studies, Photovoice was used as a community based participatory approach to understanding experiences related to HIV (PrEP usage, stigma) within the target populations. Photovoice traditionally follows a step-by-step process that involves community members working together. First, participants collaborate to identify photo assignments, determining the topics and themes for their photos. Second, each participant captures photos related to their assignments and shares them with the group. Third, through facilitated, empowerment-based discussions, participants ascribe meaning to their photos, discussing how they relate to community issues. Finally, participants organize a photo exhibition and community forum to educate others about their community's needs, assets, and priorities, and to identify actions for addressing them.<sup>85,86</sup>

The included studies all generally collected data from audio recordings of the photovoice sessions (discussions and group presentations of photos) that were then analyzed using a systematic qualitative process to identify thematic trends. Specifically, text transcripts and audio recordings of all participant study sessions were analyzed using strategies of thematic analysis to capture major ideas across and within participant stories. These themes were then utilized to help create a narrative table that outlined each participant, their photos, and the stories they told around each photo.<sup>79-83</sup>

Some studies provide participants with their own questions predeveloped question to guide the photography process, while other studies utilized a protocol that collaboratively

developed three “photo assignments” alongside the participants and study facilitators.<sup>79</sup> The How Can We PrEP photovoice study conducted by LeMasters *et al.* to understand the daily lives of Black MSM on PrEP in the “Triangle Region” of North Carolina (a region in NC defined by three major research universities: The University of North Carolina-Chapel Hill (UNC-CH), Duke University, and North Carolina State University) with special consideration for barriers and facilitators of PrEP usage.<sup>80</sup> The photo assignment prompts LeMasters *et al.* developed alongside participants and facilitators were: 1) What am I lacking when it comes to PrEP?; 2) How does PrEP fit into my life?; and 3) How can my community support me on PrEP? Each prompt was the focus of a single photo discussion session.<sup>80</sup> The three photo assignments were followed by discussion sessions that utilized an adapted version of Wallerstein’s 1994 SHOWED model (Figure ).<sup>80,87</sup> This approach incorporated aspects of Wang and Burris’ 1999 photovoice techniques as a guideline for the group conversation.<sup>80,85</sup> SHOWED is a Photovoice facilitation technique which includes: 1) discussing a picture literally, 2) identifying how a picture relates to relevant issues, and 3) developing actions that could be taken to address those issues.<sup>87</sup>

The expanded SHOWED Model developed by as LeMasters *et al.* represents a structured six steps approach used to facilitate photo discussions and promote understanding and action.<sup>80</sup> First, participants describe what they see in the photo, including both the image itself and the underlying story (S). Next, they explore what is really happening, delving deeper into the story's meaning and the emotions involved (H). Then, they discuss how the photo relates to their own lives and community (O). After that, they analyze the root causes of the issue, considering individual, family, community, and societal levels (W). Following this, they identify how their new understanding can empower them to take action, both individually and collectively (E). Finally, they discuss potential actions and how they can work together to create positive change

(D).<sup>80</sup> LeMasters *et al.* implemented the adapted to gather information related to understand Black MSM community's needs and experiences regarding PrEP in the "Triangle Region" of North Carolina.<sup>80</sup>

The studies reviewed highlight Photovoice as an effective empowerment tool for engaging participants in identifying, capturing, and discussing their experiences and perspectives related to HIV treatment and prevention. One study conducted among Black MSM in North Carolina, US aimed to describe the needs, assets, and priorities of Black MSM with HIV who live in the southern US to identify actions to improve their health by addressing their needs and priorities using photovoice, a qualitative, participatory, and exploratory research methodology. The study also aimed to assess the impacts of photovoice as an action-oriented research method. In the study, participants attended one orientation session and participated in four photo discussion sessions. Participants decided upon the following four photo assignments: triggers, success, the future, and coping.<sup>79</sup>

One study focused on stigma, as it relates people living with HIV/AIDS in the United States southeastern region, and uncovered intersecting themes of internalized stigma including: medical, social support, church, and self.<sup>83</sup> The study analyzed audio-recordings from all sessions and coded them for systematic qualitative analysis process to develop key themes. Themes were identified by completing a standardized internalized stigma scale then researchers triangulated the text from transcripts with photos and the emerged themes to tell a cohesive story for each participant's final display.<sup>83</sup> Overall, the researchers analyzed the data using strategies of theme analysis, to capture major ideas across and within participant stories, created a narrative table that outlined each participant, their photos, and the stories they told around each photo. Pichon *et al.*, Snap Out Stigma intervention, created a safe space for PLWH to share lived

experiences of stigmatization.<sup>83</sup> Specifically Pichon *et al.*, note that Photovoice has the ability to facilitate community dialogue and establish safe spaces for PLWH and identify social determinants of HIV.<sup>83</sup>

Utilizing photovoice and the adapted SHOWED model LeMasters *et al.* were able to identify themes and highlight structural and social factors related to stigma experienced by Black MSM and PrEP use and adherence, including experiences of stigma related to PrEP itself.<sup>80</sup> Research across multiple studies found that photovoice facilitated numerous dialogue topics ranging from healing and recovery, managing HIV disease, to overcoming underlying factors of social determinants of HIV.<sup>79–83</sup>

### ***Theater***

Among the papers in this review one of the most common forms of art used to promote HIV treatment and prevention was theater. Of the 18 papers identified 5 (28%) studies or projects that implemented Theater programs. Participatory drama provides a way to communicate about health-related issues in a non-judgmental and culturally appropriate way that have paved the way for many HIV and AIDS communication projects occurring in multi-cultural contexts.<sup>88</sup> Of the included papers that cited theater, three offer reviews of internationally implemented programs for health and healing related to addressing HIV and LGBTQ+ life among adolescents. Two of the papers were systematic reviews offering formative guidelines for implementing theater-based programs for HIV treatment and prevention.<sup>88,89</sup> One article offers a model of LGBTQ youth theater programs.<sup>90</sup>

To determine the impacts of a two-week theater camp program on medical treatment and feelings of stigma researchers in Eswatini in collaboration with a non-profit organization of professional teachers, actors, and musicians implemented a quasi-experimental design CBPAR approach among adolescents and young adults (ages 13– 25 years) with HIV.<sup>17</sup> Participants



were actively enrolled at the Baylor College of Medicine- Bristol-Myers Squibb Children's Clinical Centre of Excellence in Mbabane, Eswatini. Camp sessions ran Monday through Friday for seven hours. The theater camp curriculum featured a variety of activities designed to engage participants and build camaraderie. These included group bonding through games, prompt-based improvisation, short skits, lyric writing, and delivering speeches to the group. During sessions, participants worked with teachers to develop an original plot, complete with music and lyrics. The aim was to encourage self-expression while fostering a sense of friendship and community among the group.

Pre- and post-camp surveys were administered to the participants to assess perceived stigma and impact of the camp. Twenty-five percent showed a substantial decrease in HIV viral load within six months of completing the theater camp program, while only 10% showed a substantial increase. The theater program piloted in Eswatini shows creative arts programming, even when not directly addressing HIV, has beneficial psychosocial effects, contributes to community building, and potentially enhances the effectiveness of medical treatment.

Pufahl *et al.* developed Theatre Connect (TC), a program designed for adolescents aged 13–18 years who identify as LGBTQQ.<sup>90</sup> Participants are referred into the program by clinicians and recruited through communications with local schools and LGBTQQ organizations. TC generally runs three seasons a year, with each season consisting of eight weekly two-hour “rehearsals.” On average, there have been about 10 participants registered per season, with an average participant age of 15 years. Approximately 90 youth have participated in the program over its life span.<sup>90</sup> During the after-school theater camp the mental health team alongside the facilitators from TC help connect youth to available community and clinical resources to ensure they receive critical support. Researchers propose that mental health or theatre organizations

aiming to establish youth theatre programs in their local communities prioritize safe and ethical practices. This can be achieved by creating sustainable partnerships between mental health counselors, experienced theatre practitioners, and local support organizations.<sup>90</sup> Additionally, it is recommended to develop a clear contract between participants and facilitators outlining program goals and the scope of practice. Activities within the program should be limited to the first through the fourth rings of the drama spiral. Furthermore, the focus should be on "play" and drama/theatre skill-building rather than LGBTQQ topics. Finally, organizations are encouraged to consult the TC Collaborative Theatre Model developed by Pufahl *et al.* for additional guidance and future iterations of TC or similar programs.<sup>90</sup> TC facilitators observed the greatest youth engagement and strongest group cohesion during sessions that emphasized playful drama games and exercises while limiting the inclusion of personal narrative during group rehearsal activities.

Dalrymple's DramaAide program is a participatory theatre organization that uses drama to explore HIV and AIDS themes to highlight. Dalrymple's program includes two primary activities: a drama workshop and educational theater. The drama workshop (facilitated in school classrooms or playgrounds) is interactive and participatory, and it includes games, different role-plays and discussion reflecting on the theme of the workshop. The educational theatre aspect involves plays, songs, dances, and poetry that are devised and presented by young people for their peers. Evidence from Dalrymple's reports (2004, 2006) suggests that where young people are empowered through the program, they may clash with their more conservative parents and other authority figures and be prevented from making the changes that they desire in their own lives.<sup>88</sup> Collectively these studies aim to propose best practices for public health researchers and

community youth leaders interested in starting or refining existing theater programs related to health and wellness.<sup>88-90</sup>

### ***Performance***

Performance as resource for HIV treatment and prevention was cited in two (11%) of the papers that were included in this review.<sup>91,92</sup> As defined by Merriam Webster is *performance*, ‘[3]- *a*: the action of representing a character in a play, *b*: a public presentation or exhibition.’<sup>93</sup> Utilizing sociology and ethnographic research methodologies, Bailey, examines and reports participation in Ballroom community or ‘‘house ball culture,’’ and the associated performance mechanisms as an effective tool for social support and HIV treatment and prevention. Bailey highlights three specific aspects of ballroom community practices as HIV/AIDS interventions: the social epistemology of ballroom culture, kinship and social support, and Black queer performance and HIV/AIDS prevention balls. Ballroom culture and participation among Black and Latino communities is comprised of two key components that support the community to promote HIV/AIDS treatment and prevention strategies directly and indirectly: (flamboyant competitive ball rituals and houses, and the anchoring family-like structures that produce these rituals of performance).<sup>91</sup>

Using ethnographic research methodology to examine the relationship between Ballroom culture and HIV treatment and prevention allowed for qualitative data collection related to social and behavioral sciences.<sup>91</sup> Ballroom participants are representative of many gender expressions and sexualities. Ballroom participants include members who are PLWH and people who are HIV negative.<sup>91</sup> The paper highlights ‘‘walking balls’’ or attending balls as a key element of performance and dance in Ballroom. The paper reports that ‘‘houses’’ or ‘‘families’’ within house ball culture creates subjectivities and familial roles based on an egalitarian gender/sexual identity

system that offers more expansive gender and sexual identities for Ballroom participants to choose from.<sup>91</sup>

HIV/AIDS prevention balls are directly funded by CBOs and aimed at addressing the HIV/AIDS epidemic directly. During such “prevention balls” the categories or themes of the ball will correlate with HIV/AIDS treatment and prevention strategies.<sup>91</sup> Bailey for example, notes a description of a 2005 ball category from the Love is the Message Ball in Los Angeles. The flyer description read:

*[School Boy Realness—Let’s see if U were paying attention in Sex Ed. Bring us School Boy realness w/a safe sex production. Props a must and you will be graded on your project and knowledge.*

VS.

*Executive—U have been promoted to CEO of a condom company of your choice. U must have a prop and be prepared to sell your product to the board.]*

Bailey’s report supports findings that participation in Ballroom culture provides a safe space for Black queer communities to have social support, too freely express themselves, and to engage in HIV prevention tactics. The performance of Ballroom allows for Black queer people to label and express themselves freely in gender and sexuality categories that only exist in Ballroom community. Ballroom participants define themselves based on the categories they walk/ perform. The combination of performance and kinship according to Bailey act as cultural practices that allow Ballroom community members to participate directly in HIV/AIDS treatment and prevention strategies.

The second study carried out by Boneh and Jaganath across Ghana engaged people with HIV/AIDS in the Process and Collaboration for Empowerment and Discussion (PACED) project

to empower and generate discussion about structural and contextual barriers in the context of HIV/AIDS.<sup>92</sup> Boneh and Jaganath project aims to suggest a shift toward a more participatory, communal, and empowering approach to HIV treatment and prevention education through the use of art and performance. Boneh and Jaganath employed a collaborative process of iterative stages to engage and build relationships with five Ghanaian popular artists and five individuals living with HIV/AIDS.<sup>92</sup> Boneh and Jaganath coined this process, the PACED approach, included the following unique stages: (1) Knowledge acquisition, (2) Elimination of barriers, (3) Depth of understanding, (4) Empowerment, (5) Theme development, (6) Processing, (7) Rehearsals and production, and (8) Performance. This collaborative approach aimed to empower participants and facilitate discussions on HIV/AIDS education.<sup>92</sup>

Target populations of the for the final performances were young adults (age 16- to 35-years) from poor rural and urban communities. Data from focus group discussions held on the day after the performance in 4 of the towns where the final performances were held. Data collection did not include a pretest.<sup>92</sup> The paper reports entertainment–education an effective tool for triggering change in society, however, research note for sustained behavioral changes to occur, basic elements of the performance education must be integrated into the proposed intervention strategy. The study found that performance was an effective tool to engage participants and facilitate community discussion about HIV treatment and structural and contextual barriers. Focus group discussions and interviews indicate that performance allowed participants and community members to feel empowered when determining how to articulate contextual barriers to HIV prevention discussions around.<sup>92</sup> These finding were summarized into three key elements—collective recognition, critical awareness, and vision.<sup>92</sup>

The two papers addressed suggest that performance is a viable approach to HIV treatment and prevention that can serve to empower individuals, engage community members, and facilitate dialogue of HIV/AIDS health and wellness. Bailey notes the ability to self-identify while “walking” or performing at balls is critical for members of the Ballroom community to feel a sense of self-representation. Bailey highlights that there is also an inherent understanding and recognition that HIV/AIDS treatment and prevention is a community issue. Ultimately, Boneh and Jaganath’s PACED approach redefines goals and best practices for utilizing performing arts in HIV/AIDS education. Limitations identified by Boneh and Jaganath include the lack of integrated activities before or after the performance to reinforce behavior change. Researchers Boneh and Jaganath recommend that future integrations of performance for HIV/AIDS health promotion included long term follow up.

### ***Poetry***

Poetry was identified as a creative arts-based approach to HIV treatment and prevention in two (11%) of the included papers.<sup>94,95</sup> Poetry was found to be an effective tool in increasing knowledge and overall understanding of HIV treatment and prevention among youth participants. One study conducted a community-based participatory research project by, Isler et al., titled "The Spoken Word Project" (SWP) to assess the effectiveness of using poetry in community dialogue and mobilization for HIV prevention.<sup>94</sup> The study aimed to describe the development and implementation of SWP, an HIV/AIDS pilot intervention in rural North Carolina. The Spoken Word Project was designed to improve HIV-related attitudes and self-efficacy and decrease stigma using performance poetry. Methodology for the Spoken Word Project was developed from Photovoice curriculum. Isler et al implemented SWP in two phases that consisted of spoken word trainings (three stages: (1) apathy, (2) social responsibility, (3) action) and spoken word performances (one local performance and one regional showcase). The

study identified indicators related to HIV including self-efficacy, attitudes and beliefs, and stigma among participants.

Utilizing both process evaluation and outcome evaluation strategies, Isler et al. determined that spoken word can contribute to local resources, generate community reflection, and engage a broad spectrum of performers and audiences. Student assessments were created with indicators of key domains: self-efficacy, attitudes and beliefs, and stigma.<sup>94</sup> Study findings also highlight the effects of stigma and limited community conversations about HIV in rural communities can be reduced using spoken word in social settings. Participants in the SWP training demonstrated improvement in self-efficacy and reduced stigma towards HIV, while attitudes and beliefs remained relatively unchanged. Participants in the SWP project, also expressed “understand[-ing] they have a voice in the community.” Poetry improved HIV knowledge and awareness, but attitudes and beliefs remained relatively unchanged.

In the Tell Me What You See (TMWYS), Edmondson, aimed to develop a set of innovative, flexible resources that would expand use of the youth-developed artwork beyond the juvenile justice facility where it originated to public high schools and other educational settings across the state. Utilize artwork and poetry created by incarcerated youth to promote sexually transmitted disease (STD), HIV, and hepatitis prevention with students in public high schools and juvenile justice facilities.<sup>95</sup> The core components of Edmondson’s pilot included student-generated artwork, consisting of eight posters and poetry, along with educational materials such as informational factsheets. Additionally, the program involved classroom activities and student assessments aligned with the National Health Education Standards. Health education teachers were also trained on how to use predeveloped TMWYS materials and were provided technical assistance throughout the pilot. The evaluation process Edmondson implemented included three

data collection strategies: (1) focus groups with teachers and members of the development team, (2) pre- and posttest surveys with students, (3) review of student work associated with TMWYS assignments.<sup>95</sup> Results indicated that student content knowledge and awareness of STDs, HIV, and hepatitis increased significantly after participating in TMWYS. Pre and posttest results for students indicated improvements in ability to visualize and introspectively consider the impact of risky behavior on family, friends, community, and self. Noted limitations of Edmondson's study included high price of materials, and participation gaps for students with English as a second language.<sup>95</sup>

Both Edmondson and Isler et al. relied on pre and posttests to analyze changes among study participants. TMWYS unveiled themes such as shared decision making, trust, communication, and definition of roles and responsibilities all emerged relating to the strength of the partnership and its ability to coordinate and streamline service delivery to at-risk populations.<sup>95</sup> Ultimately, the studies report that poetry has the potential to promote HIV treatment and prevention behaviors among study participants.

### ***Music and radio***

The review identified three papers (17%) that used music as a creative art form to promote HIV treatment and prevention strategies.<sup>96-98</sup> The studies found that music had positive affects for improving attitudes of HIV/AIDS, improving adherence to antiretroviral therapy (ART) and increasing HIV knowledge.

The LIVE Network (LN) is a piloted music-based messaging health intervention aimed at promoting self-management of adherence to antiretroviral therapy (ART) among PLWH.<sup>96</sup> LN is a 70-minute audio program designed to educate and motivate PLWH to adhere to ART treatment and manage medication-related symptoms. LN implements a DJ talk show format, featuring expert advice from infectious disease physicians, nurse practitioners, and nurse educators who



utilize motivational interviewing techniques to respond to "callers" and provide advice and health information related to HIV. The health experts suggest strategies to improve adherence and self-management skills. LN includes original music ranging from jingles to talk segments that address topics such as self-efficacy, medication adherence, HIV symptom management, and coping strategies. Based on Social Cognitive Theory, LN researchers included persuasive messages conveyed throughout the songs such as "you can do it" (self-efficacy) and "take every dose every day" (adherence).<sup>96</sup> LN participants also have access to a 1- 800 number for support and questions. <sup>96</sup> Overall, the LN program aims to empower individuals with HIV/AIDS to take control of their treatment and well-being. The 2009 LN study was conducted in a larger urban city in the Southeast United States at an infectious disease clinic primarily serving Black/African American clients (78%).<sup>96</sup> Utilizing pill counts, CD4 levels and viral load as indicators LN study team piloted the music-based messaging program to address the efficacy, feasibility, and acceptability of music for HIV treatment and prevention.<sup>96</sup>

At the conclusion of the LN program, study participants completed an end-line evaluation comprised of rating their satisfaction, likability, and usage of the program, as well as offering suggestions for improvement. LN study found that individuals with higher rates of depressive symptoms at baseline had lower levels of therapeutic drug levels at the end of the study.<sup>96</sup> In the LN study adherence to HIV treatment plan declined over time for each group, Improvement in self-efficacy.<sup>96</sup> However the drop in ART adherence was greater among participants who did not participate in the LN intervention compared to those engaged in LN.

Another article describes the formative research approach of the Community Media for Development program (2014), which, included music alongside comics as an art form to promote HIV treatment and prevention in a semi urban region of Mozambique.<sup>98</sup> The

Community Media for Development program Project was a participatory process implemented among school aged children and at local youth centers to worked with local music group *Sigauque* to create two songs about HIV. The formative results suggest that music and comics are effective tools to improve a sense of pride among youth and increase attitudes toward practicing and promoting HIV treatment and prevention strategies. Overall, the project increased dialogue among youth, and the greater community, about HIV. The music and comic project highlighted new perspectives and understanding among youth and the community about gender-based violence and alcohol as well as identifying risk behaviors.<sup>98</sup> The Community Media for Development program promoted a greater awareness among young women about the HIV risks specific to females and improved the ability to prevent HIV.<sup>98</sup> Overall, the literature reviewed deems use of music promising in ART adherence, increasing knowledge attitudes and beliefs of HIV/AIDS prevention and promote self-efficacy among adolescents living with and at-risk HIV.<sup>96-98</sup>

### ***Sculpture and visual art***

Visual art was present in only one (5%) of the selected papers as a tool for HIV/AIDS awareness.<sup>99</sup> The paper describes a longitudinal multistage research process that ultimately integrated the use of soap to make visual art sculptures that tell the nuanced story of how woman and men navigate HIV treatment and prevention differently. The 'Transparent Soap' project aimed to use sculpture as a new way to add art into communities and include viewers as participants in the construction of meaning and interpretation of the art.<sup>99</sup> In the study project, clay sculptures were created depicting men with erect penises as a way to emphasize the relationship between heterosexual sex and high rates of female infection, a couple embracing to convey ideas of faithfulness in relationships, and a woman holding a book to convey the value of women's education in HIV/AIDS awareness.

The 'Transparent Soap' study was conducted across Uganda and highlighted how sculpture can be a useful tool in promoting HIV/AIDS awareness by decreasing barriers and addressing stigma related.<sup>99</sup> For sculptures to serve as effective tool for health promotion, sculptures and visual arts must possess certain qualities according to the 'Transparent Soap' study. <sup>99</sup> They need to be visually appealing, allowing them to capture the audience's attention. Interactivity is key, as it encourages engagement and participation from viewers. Additionally, affordability and ease of transport are crucial to ensure accessibility to a wide range of audiences. <sup>99</sup> Sculptures should also be designed to cater to both literate and illiterate individuals, accommodating diverse levels of literacy. However, beyond their physical attributes, the content and themes addressed by the sculptures are equally important. To be impactful, they must resonate with the communities they aim to serve. <sup>99</sup> This requires collaboration between artists and community members to ensure that sculptures address relevant issues appropriately and effectively. Involving the community in the creative process can produce sculptures that better reflect the lived experiences and concerns of the people they represent, ultimately improving their relevance and impact as art to promote HIV health and healing.<sup>99</sup>

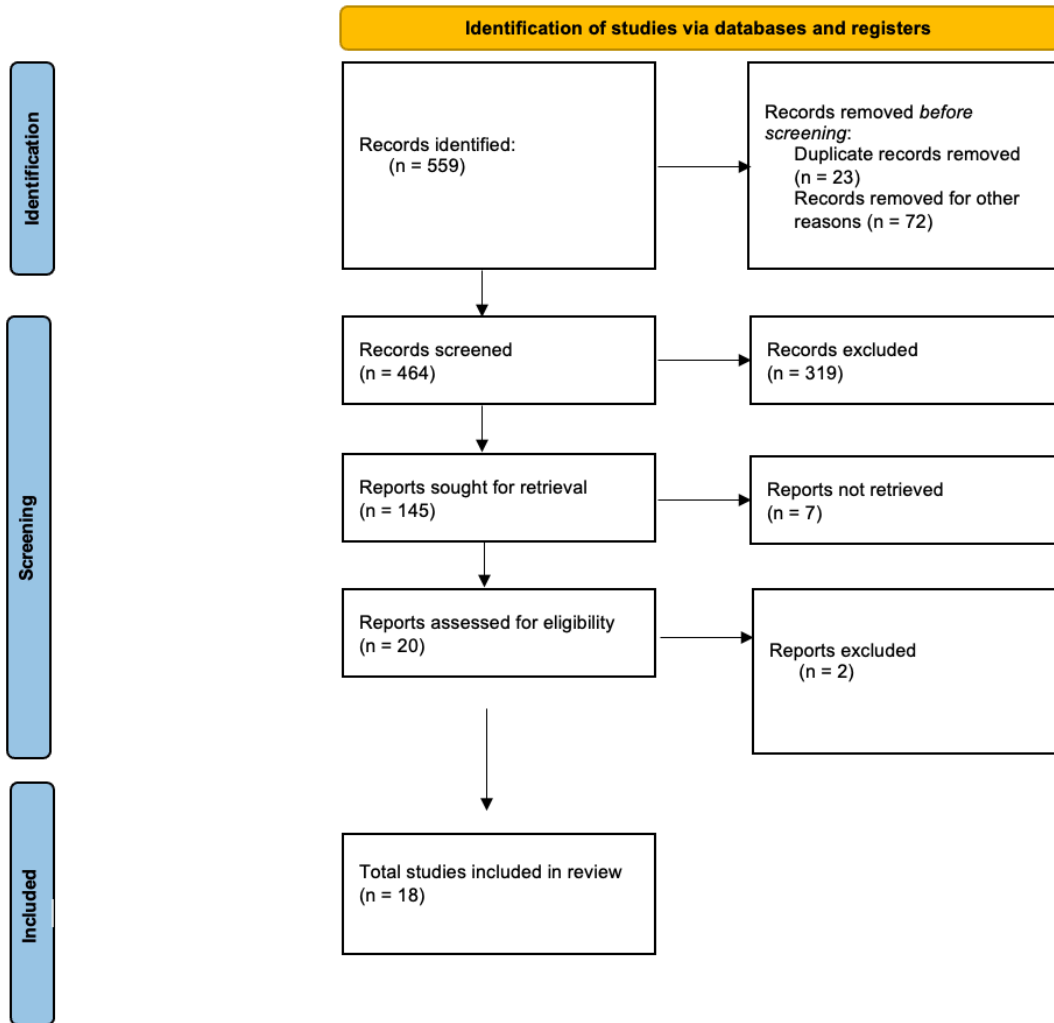


Figure 1 - Flow Diagram- Adapted from: *The PRISMA 2020*<sup>100-102</sup>

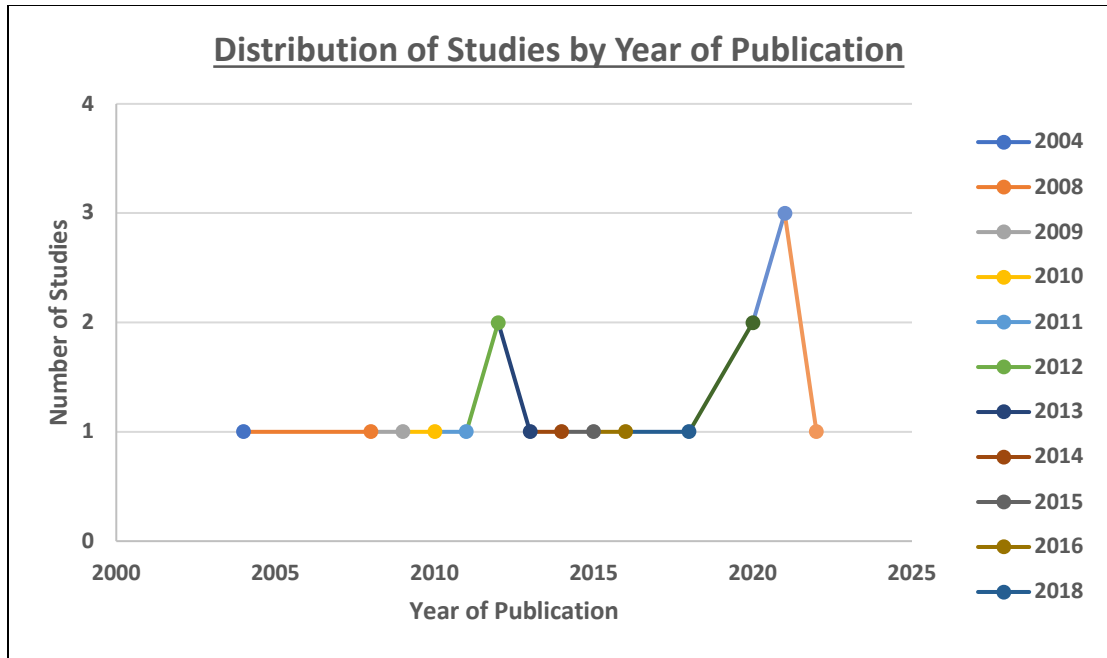


Figure 2 - Plot Graph Timeline of Study Publication Dates

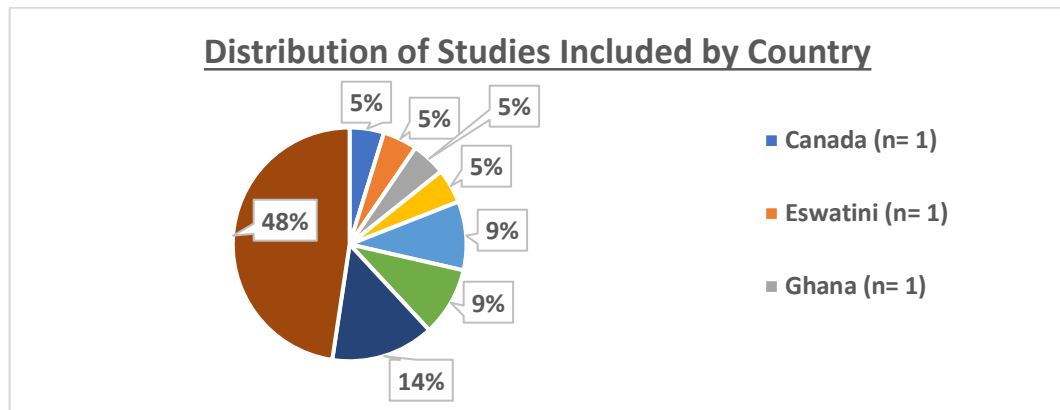


Figure 3 - Pie Chart Distribution of Studies Included by Country

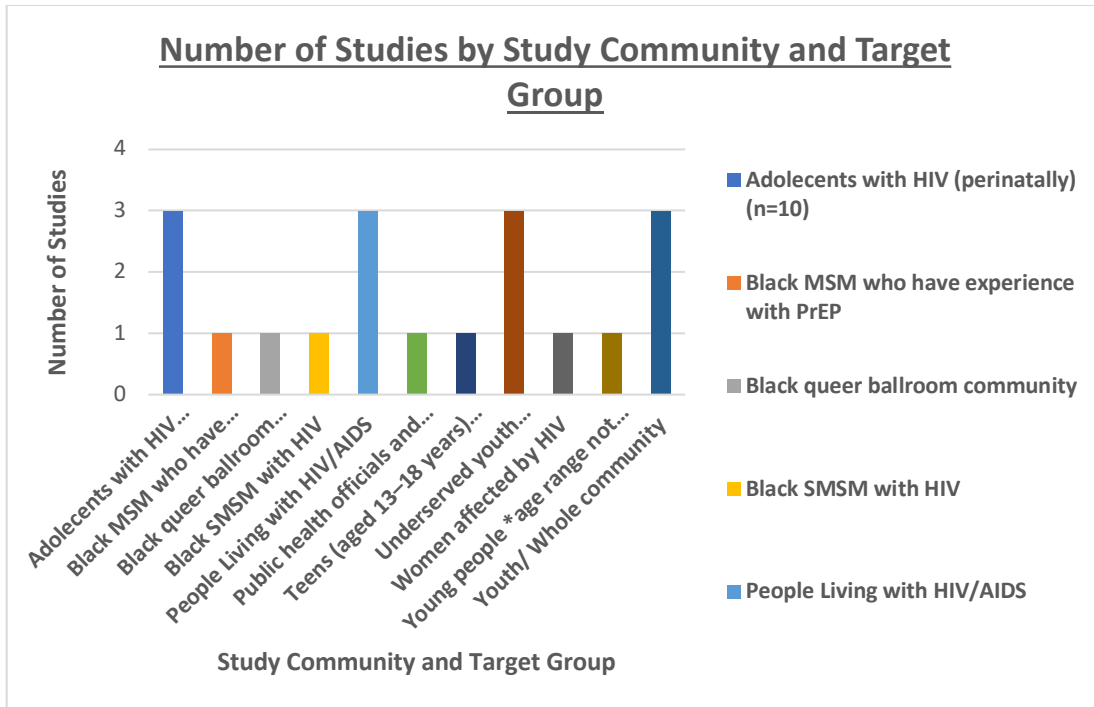


Figure 4 - Bar Graph of Studies by Study Community and Target Group

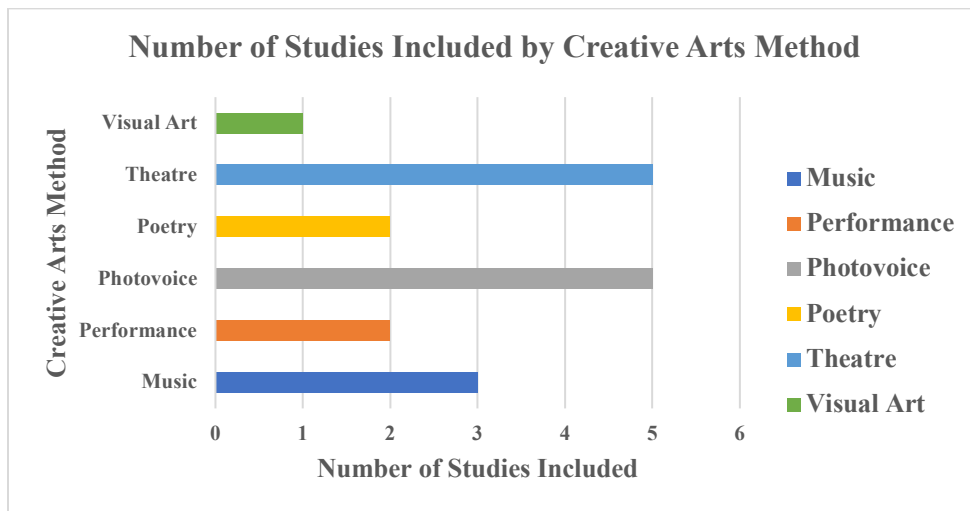


Figure 5 - Bar Graph of Studies Included by Creative Arts Method

The SHOWED Model		
<b>S</b>	What do we SEE in this photo?	Be concrete—describe the photo and the underlying story.
<b>H</b>	What is really HAPPENING?	Go deeper—identify what the story represents and how people in the story feel.
<b>O</b>	How does this relate to OUR lives and OUR community?	Take a broader view—discuss how we (in the room and in our community) have similar or different experiences.
<b>W</b>	WHY does this problem exist?	Move to analysis—seek to understand the root cause of the issue, at individual, family, community, and societal levels.
<b>E</b>	How can we become EMPOWERED with this new understanding?	Return to the individual—identify how our knowledge can move us to action.
<b>D</b>	What can we DO to change this?	Consider action—discuss how we, personally and collectively, can act to make change.

Figure 6 - The SHOWED Mode from LeMasters et al. (adapted from Wallerstein, 1994, Wang and Burris 1999)<sup>80,85,87</sup>

## **Chapter 4. DISCUSSION and RECOMMENDATIONS**

In this discussion, I will be putting the findings of this scoping review in the context of the greater public health fight towards Ending the HIV Epidemic. This study aimed to address gaps in literature related to HIV treatment and prevention strategies by asking two main questions: how creative arts-based approaches can be used for HIV treatment and prevention among Black queer youth populations, and how effective are these strategies among the target communities. There is a need for more youth centered programing related to HIV in general. Due to limited healthcare services provided adolescence friendly spaces specifically, according to the WHO “youth are living with HIV have the worse access to antiretroviral treatment retention in care and viral suppression.<sup>4</sup>

According to the WHO, one of the main reasons adolescents with HIV/AIDS experience poorer health outcomes is the lack of services tailored to their needs, such as those offering

psychosocial support and interventions.<sup>4</sup> Implementing creative arts into healthcare practices for HIV treatment and prevention can be a unique and a necessary component of meeting UN 2030 “95-95-95”. Creative art directly aligns with the UNAIDS Fast-Track goal to broaden “options for service delivery to reduce the burden on strained health systems and extend the reach of services, including greater use of community-based and rights-based approaches and new partnerships.”<sup>103</sup>

This review identified a wide range of creative arts-based approaches that have been used globally within HIV treatment and prevention across global Black populations. This scoping review explores academic literature related to creative art practices as the intervention / exposure of interest and identified outcome of interest is the impact on HIV treatment and prevention (improved medication adherence, decreased viral load, reduced stigma). The geographic spread of the research represents data collected from eight different countries. Most of the creative arts-based approaches were identified from studies conducted across the United States.

The included studies employed six art forms creative art activities related to HIV/AIDS. Photovoice and theater-based were the most prominent among these approaches, but poetry, music, performance, visual arts, and others have been explored.

Prior research indicates that HIV prevention interventions that are specifically developed for young people are often theory based and, provide a combination of HIV knowledge and skills training and improve motivation to reduce HIV risk.<sup>104</sup> If public health official continue this model of targeted strategies to promote health then it is necessary to provide a more tailored multifaceted approach for the HIV treatment and prevention care continuum among BQYP.

Using creative art in HIV treatment and prevention strategies can prove to be a vital tool for helping end the global HIV epidemic. For BQYP specifically, implementing creative art



combined with existing HIV treatment and prevention strategies can help reduce HIV stigma, improve social and community engagement, and promote medication (ART/ PrEP) adherence. Improvements for community based messaging.<sup>96</sup> Utilizing HIV viral load as the marker, researchers found that creative art therapy had the power to engage youth in programing that encouraged medication adherence including HIV testing, PrEP uptake and ART usage.<sup>17,82,96,97,105</sup>

The implementation of Community-Based Participatory Action Research (CBPAR) has been growing in popularity as well as usage among healthcare providers and public health researchers understand patient experiences in a unique way. Previous findings indicate that CBPAR allows for better cultural understanding, improves community engagement, builds upon people personal strengths, and sheds light on community needs.<sup>104,106,107</sup>

The studies explored in this scoping review highlighted that when done with cultural humility and aspects of CBPAR, implementation of creative arts based programing and activities has the ability to decrease stigma related to HIV treatment and prevention at the individual, community and nationwide level.<sup>17,81–83,94,98,99,105</sup> As a leading way to reduce HIV stigma, existing community-based programs use trained facilitators or peer educators and now newly emerging programs utilize PLWHA as program lead or collaborators.<sup>104</sup>

In previous studies, rural community members had been found to have more HIV stigma so there is a greater need to establishing public health intervention programs.<sup>104,108–112</sup> HIV prevention efforts targeted for young people in rural Black and African American communities can require additional layers of specific tailor to be effective.<sup>113</sup> Implementing creative arts as a CBPA activity is a leading approach to target rural Black and African American communities.

Creative arts overall had the potential to decrease stigma related to HIV among activity participants. Creative art activities were able to facilitate dialogue and engage community members in discussions regarding navigating HIV treatment, barriers to care, and PrEP uptake and accessibility.<sup>79,82,83,88,91,92,94,95,98,99,105,114</sup> Ballroom culture provides a safe and fulfilling place for Black Queer communities to express their gender and sexuality freely. These more expansive gender and sexual identities are not available to people in the “outside” world and allows for BQYP, and other participants in ballroom culture to have a range of possibility to self-identify in a more free and inclusive community.<sup>92</sup>

Photovoice, a common CBPAR practice, is a powerful tool for developing community needs assessments among and can specifically be implemented among BQYP to uncover culturally appropriate approaches to promote health and healing related to HIV care and prevention among BQYP.<sup>115</sup> Photovoice can provide insights into identifying structural barriers in HIV treatment and prevention and contribute to cultivating rich community. Specifically, photography and the process of participating in photovoice can serve as a tool for advocacy, as well as stigma reduction at the personal, interpersonal and structural level.<sup>79–83</sup>

This scoping review identified previous studies utilizing drama have prevented to improve self-esteem. Baim’s drama spiral adds further guidance for facilitating drama activities in a manner that deemphasizes personal sharing in vulnerable populations.<sup>116</sup>

Results of this review indicate that HIV healthcare interventions that rely on creative arts influenced several aspects of HIV prevention motivation, behavioral skills, and condom use and HIV testing behaviors. This research demonstrates that the incorporation of music into HIV prevention and treatment interventions, for BQYP, seems acceptable and feasible with the

potential ability to address ART adherence and self-efficacy however more research is needed to support limited the limited literature.<sup>98</sup>

Performance theory is transdisciplinary and boundary-breaking, and it has the potential to help produce an understanding of social problems in more nuanced ways.<sup>117</sup> The use of performance can help promoted visibility and self-expression for BQYP who are navigating HIV as a part of their daily lives.<sup>91,92</sup> These more expansive gender and sexual identities are not available to people in the “outside” world.<sup>91</sup> The performance methodology from Boneh and Jaganath PACED report produced evidence of entertainment education as a way of initiating change and if the methodology is strengthened and adapted entertainment education could be a viable creative art form to address HIV treatment and prevention for BQYP.<sup>92</sup>

TMWYS initiative emerged as a leading piece of literature offering support and key methodology for actively engaging young people and established key precedents in the fields of HIV/AIDS treatment and prevention research and medicine.<sup>95</sup>

Creative art implemented strategically alongside existing HIV treatment and prevention care continuum has the potential to serves as the novel approach needed to help reduce staggering rates of HIV, address HIV and LGBTQ+ stigma and promote PrEP uptake among BQYP.

### **Limitations**

Strengths of this scoping review include the widespread nature of data collected from a global perspective including diverse study populations. This review aimed to provide a breath of knowledge related to creative arts in HIV treatment and prevention rather than a depth of information into each type of artistic method. This review only included studies written in English. The strict inclusion criteria could have eliminated relevant studies. The sampling represents a hard-to-reach subsector of the population that is particularly disappointedly affected

by HIV. This study did not examine the potential economic costs for provision of creative art-based approaches for HIV care.

## **Recommendations**

The Black HIV/AIDS crisis is not over despite popular narratives that the height of the HIV/AIDS crisis is behind us. Creative art can serve as the bridge to highlight the stories and narratives of young Black queer folks navigating HIV treatment and prevention.

Funding can continue to be a significant barrier to the widespread implementation of creative art strategies for HIV treatment and prevention among BQYP. There is an overall lack of a [standardized](#) approach to art in healthcare or HIV specifically. There is an urge for public health researchers to establish specific evaluation criteria and key indicator measures related to art as a treatment for HIV treatment and prevention in clinical and nonclinical settings. This will allow for a growing source of empirically supported data to drive further implementations of novel approaches to HIV for vulnerable communities including BQYP. Additionally, more research is needed to understand the contributing factors to high rates of new HIV diagnosis among younger communities. Overall to produce this necessary body of medical work and public health research, it is recommended to explore sustainable funding sources to support the integration of creative arts into HIV programs targeting this population.

There is a current call to action to make age-disaggregate data available for key populations, following the publication and synthesis of current progress made on the state of global Adolescent Sexual and Reproductive Health Rights (ASRHR). Additionally public health officials at WHO and UN should work together to define a universal standard of age cut off markers for young people.

## **Public Health Implications**

The addition of more creative arts alongside side current methods of HIV treatment and prevention has the ability to support public health efforts towards the Sustainable Development Goals 2030 and the current UN goal for HIV is to reach 95-95-95 by 2030.<sup>118,119</sup>

This review contributes to the following Sustainable Development Goals 2030:

### *No Poverty*

- (a) SDG 1; through partnerships for co-production artisans will be empowered to earn more by way of improved skills and knowledge on how to deal with challenges related to HIV/AIDS thus strengthening the fight against poverty.<sup>16</sup>

### *Good Health and Wellbeing*

- (b) SDG3; ensuring good health among young artisan communities as applied sculptural practice will help minimize stigma and discrimination, hence facilitating social change.<sup>16</sup>

### *Decent Work and Economic Growth*

- (c) SDG 8; Increasing the potential of young people to earn and work in decent positions in workshops with improved skills and applied knowledge; Minimizing work exploitation due to inadequate skills.<sup>16</sup>

### *Partnerships for the Goals*

- (d) SDG17; Promoting collaboration for empowerment and social change through partnerships between Applied artists and artisans meant for improved production to induce improved and sustainable livelihoods.<sup>16</sup>

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